

**THE AMERICAN HEALTH CARE CRISIS:  
A VIEW FROM FOUR COMMUNITIES**

---

**HEARINGS  
OF THE  
COMMITTEE ON  
LABOR AND HUMAN RESOURCES  
UNITED STATES SENATE  
ONE HUNDRED FIRST CONGRESS  
FIRST SESSION  
ON  
EXAMINING THE HEALTH CARE CRISIS IN AMERICA**

---

DECEMBER 11, 1989, BRONX, NY  
DECEMBER 12, 1989, LOS ANGELES, CA  
DECEMBER 13, 1989, MAPLEWOOD, MO  
DECEMBER 14, 1989, SPARTA, GA

---

Printed for the use of the Committee on Labor and Human Resources



U.S. GOVERNMENT PRINTING OFFICE

WASHINGTON : 1990

25-256

---

For sale by the Superintendent of Documents, Congressional Sales Office  
U.S. Government Printing Office, Washington, DC 20402

## COMMITTEE ON LABOR AND HUMAN RESOURCES

EDWARD M. KENNEDY, Massachusetts, *Chairman*

CLAIBORNE PELL, Rhode Island

HOWARD M. METZENBAUM, Ohio

SPARK M. MATSUNAGA, Hawaii

CHRISTOPHER J. DODD, Connecticut

PAUL SIMON, Illinois

TOM HARKIN, Iowa

BROCK ADAMS, Washington

BARBARA A. MIKULSKI, Maryland

ORRIN G. HATCH, Utah

NANCY LANDON KASSEBAUM, Kansas

JIM JEFFORDS, Vermont

DAN COATS, Indiana

STROM THURMOND, South Carolina

DAVE DURENBERGER, Minnesota

THAD COCHRAN, Mississippi

NICK LITTLEFIELD, *Staff Director and Chief Counsel*

KRISTINE A. IVERSON, *Minority Staff Director*

Public Laws: 101<sup>st</sup> Congress / 1<sup>st</sup> Session / Senate  
Hearings / 1989

## CONTENTS

### STATEMENTS

#### AIDS, DRUGS, AND URBAN HEALTH CRISIS

MONDAY, DECEMBER 11, 1989, BRONX, NY

	Page
Kennedy, Hon. Edward M., prepared statement .....	2
Jose, Fernando, and Guy, individuals with HIV disease, accompanied by Jossie Rigel, a social worker .....	6
Ernst, Jerome, M.D., director of AIDS services, Bronx-Lebanon Hospital .....	12
Lynn, Stephen, M.D., director of emergency medicine, St. Luke's/Roosevelt Hospital, and chairman, Task Force on Overcrowding, American College of Emergency Physicians .....	15
Dinkins, David, mayor-elect, City of New York, Manhattan Borough president	22

### ADDITIONAL MATERIAL

Articles, publications, reports, charts, etc.:

The Crisis in AIDS Care: A Call to Action by Citizens Commission on AIDS, for New York City and Northern New Jersey, March 1989 .....	27
AIDS: The Challenge Facing the HHC System by New York City Health and Hospitals Corporation, August 1, 1989 .....	36
Federal Spending on AIDS—How much is Enough? from the New Eng- land Journal of Medicine Editorials, vol. 320, No. 24, pp. 1623-1624, June 15, 1989 .....	52
Executive Summary, a report from Janet L. Shikles, director, Health Financing and Policy Issues, GAO, Human Resources Division, Wash- ington, DC .....	54
A Comparative Analysis of AIDS Service Demonstration Projects in Los Angeles, Miami, New York, and San Francisco, October 16, 1989, sub- mitted to the Health Resources and Services Administration by Rox- anne Andrews, project manager; Bonnie Preston, project analyst; Embry Howell, project director; and Margaret Keyes, project analyst, Systemetrics/McGraw-Hill, Inc. ....	58
Chart of the Medicaidization of AIDS, by Jesse Green, Ph.D., and Peter Arno, Ph.D. ....	65
The 1987 U.S. Hospital AIDS Survey by Dennis P. Andrulis, MPH, Ph.D.; Virginia Beers Weslowski, MPA; and Larry S. Gage, JD, JAMA, August 11, 1989, vol. 262, No. 6 .....	66
Emergency Rooms Overwhelmed As New York's Poor Get Sicker, article from the New York Times, December 19, 1988 by Howard W. French .....	80
AIDS Study: A Warning of Epidemic in the Bronx, article from the New York Times, February 15, 1989 by Bruce Lambert .....	82
AIDS Drives Jobs Away, Study Says, article from the New York Times, March 7, 1989 by Bruce Lambert .....	83
AIDS in a Deficit Year: More Plans Than Money, article from the New York Times, April 23, 1989 by Bruce Lambert .....	84
Families of Children with HIV Infection—What Families are Saying, an article from the Association for the Care of Children's Health, Wash- ington, DC .....	85
Kennedy 10-point Action Plan for AIDS Care Services, proposed AIDS care initiatives for 1990 .....	87

(III)

CMS Library  
C2-07-13  
7500 Security Blvd.  
Baltimore, Maryland 21244

# IV

## AMERICAN HEALTH CARE CRISIS: THE ELDERLY AND THE UNINSURED

TUESDAY, DECEMBER 12, 1989, LOS ANGELES, CA

	Page
Krause, Jim, printer, San Dimas, CA .....	95
Hanlon, Carolyn, accompanied by her husband, John Albert Thomas Hanlon ..	99
Van Tassell, Donna.....	101
Gates, Robert, director, Health Services, Los Angeles County, Los Angeles, CA	104
McCarthy, Gene, paramedic coordinator, Los Angeles County Fire Department, Los Angeles, CA, accompanied by Bob Hook, paramedic driver .....	108
Sokolov, Jacque, vice president and medical director, Southern California Edison Company .....	112

## HEALTH CARE CRISIS IN INDUSTRIAL AMERICA

WEDNESDAY, DECEMBER 13, 1989, MAPLEWOOD, MO

Kennedy, Hon. Edward M., prepared statement .....	120
Clay, William, a U.S. Congressman from the State of Missouri.....	122
McDaniel, Brigett, St. Louis, MO; Neal Baretta, Kansas City, MO; and, Edward and Paige Hoffman, Jennings, MO.....	123
Kerr, Betty Jean, executive director, People's Health Center, Inc., St. Louis, MO; Edna Dell Weinell, executive director, Family Care Center of Carondelet, Carondelet, MO.....	132
Prepared statement of: Ms. Weinell (with attachments) .....	138

## HEALTH CARE CRISIS IN RURAL AMERICA

THURSDAY, DECEMBER 14, 1989, SPARTA, GA

Baity, Joan, Sandersville, GA.....	170
Brown, Debra, Greensboro, GA .....	174
Sheppard, Joseph, Sparta, GA.....	178
Holloway, Dr. Ted, director, Southeast Health Unit, Georgia Department of Human Resources .....	182
Dollack, Gary, administrator, Hancock Memorial Hospital Sparta, GA .....	187
Green, Dr. George, physician, medical educator and public official.....	191
Walker, Christie, Hancock County, GA.....	191
MacAfee, Lillian, Washington County, GA.....	191
Moore, Howard, Macon, GA.....	192
Smith, Cynthia .....	192
Spell, Alton, Jr., Louisville, GA .....	193
Warren, Lily, Sparta, GA.....	193
Holloway, Dr. Ted, director, Southeast Health Unit of the Georgia Department of Human Resources .....	226
Kennedy, Hon. Edward M., prepared statement on Health Care Crisis in America.....	209

## ADDITIONAL MATERIAL

Articles, publications, statements, etc.:

American Academy of Family Physicians position statement on Access to Health Care for the Uninsured .....	195
Emergency Fund for the Medically Indigent, Inc., Milledgeville, GA, letter to Senator Edward Kennedy from Earline Ham, dated December 14, 1989, with attached questions and answers about a local health service .....	200
Fund finding it harder to aid medically needy, article from the Union-Recorder, Tuesday, January 10, 1989, by Binky Strickland, Lifestyles editor.....	203
ACCG Policy Statements, adopted October 13, 1989, Atlanta GA.....	204
Background on America's Health Care Crisis .....	215
Legislation introduced by Senator Kennedy on the Health Care Crisis .....	221



# AIDS, DRUGS, AND THE URBAN HEALTH CARE CRISIS

---

MONDAY, DECEMBER 11, 1989

U.S. SENATE,  
COMMITTEE ON LABOR AND HUMAN RESOURCES,  
*Bronx, NY.*

The committee met, pursuant to notice, at 2:40 p.m., at the Bronx-Lebanon Hospital, Bronx, NY, Senator Edward M. Kennedy (chairman of the committee) presiding.

Present: Senator Kennedy.

Mr. FERRER. Ladies and gentlemen, it's my responsibility to bid you all welcome to the Fulton Pavilion of the new Bronx-Lebanon Hospital. You can see building going on not only around this cluster of buildings, but new building going on around the concourse pavilion, the new concourse pavilion, signifying not only a revival of this fine institution of quality health care in the South Bronx, but a corresponding revival of the Bronx itself.

Another happy responsibility I have is as this very important forum is convened for the purposes of exploring how it is that AIDS affects our ability to care for all Americans, not only those whose financial resources permit them to be cared for well and with dignity, but every American, this forum, this important meeting is taking place in what is probably becoming quickly the epicenter of AIDS in the Northeast of the South Bronx in the city of New York. There is no finer, I believe—and many, many people across this country believe—no finer champion for the cause of compassionate, decent, and affordable health care for all Americans, regardless of ability to pay, than the senior Senator from the State of Massachusetts, the one who is convening this forum and the one who I have the pleasure of presenting to you: Senator Edward M. Kennedy. [Applause.]

## OPENING STATEMENT OF SENATOR KENNEDY

The CHAIRMAN. Thank you.

We were not calling for too much order at this particular time.

I want to say that we are having a hearing of our Labor and Human Resources Committee. First of all, I want to thank Freddie Ferrer for his willingness to join us today. He has been a good friend of mine for some time. He is an individual who understands the health care crisis, not only in the Bronx but has a good feel and understanding of the challenges which all Americans are facing. He has, I think, provided very important leadership to the

people that he represents and to the patients and to those in the medical profession. I appreciate very much his presence here today.

I want to thank all of those here at the hospital: Myron Strober and Miguel Fuentes of the Bronx-Lebanon Hospital for their kindness. [Applause.]

We'll try and hold, for the rest of the afternoon, the applause, although the witnesses certainly deserve it. I thank the hospital for making the facilities available, their personnel for being willing to take the time to bring us through some of the outpatient programs, and have us meet some of those who are involved on the front lines in the battle against drug abuse and AIDS.

I admire personally the leadership that is being provided, not only by the hospital but by all the medical personnel. The nurses, the doctors, the social workers and those that are a part of the whole medical team deserve a great deal of commendation. Those that are in the training programs who are really committed to the people, their neighbors, their friends, the community, I think all of them deserve a great deal of commendation.

We also have Senator Gonzales, Assemblywoman Gloria Davis, and Herman Badillo, who have joined us here today. I'm grateful for their presence at our hearing.

[The prepared statement of Senator Kennedy follows:]

#### PREPARED STATEMENT OF SENATOR KENNEDY

With this hearing, the Senate Labor and Human Resources Committee launches an intensive, week-long examination of the state of America's health care system. In the next few days we will travel to the West Coast, to the Midwest, to the deep South, and conclude on Friday in Washington. Our purpose is to monitor the vital signs of this Nation's system for delivering essential health services to the American people.

Health care should be a basic right for all, not an expensive privilege for the few. In fact, the Nation's health care system is the fastest growing failing business in America. At the heart of what is clearly a crisis in American health care is the continuously expanding number of Americans who have no health insurance whatsoever. Thirty-seven million Americans who might need urgent medical services tomorrow would have no idea how to pay for them, because they have no health insurance. Another 60 million Americans have insurance that even the Reagan administration said was inadequate, and that could leave them bankrupt in a serious illness.

Yet, the Nation spends vast sums for health care—an incredible \$50 billion this year—double the amount spent in 1980.

We also face a crisis in the delivery of essential health services more serious than at any time since the enactment of Medicare in 1965. And all of these critical problems are compounded by AIDS and drugs.

In fact, the twin epidemics of AIDS and drugs are now threatening the very survival of health care systems in many of our Nation's major cities—and in some rural communities as well.

It is this unfolding crisis which brings us to the Bronx-Lebanon Hospital today, where 1 in 9 newborns and 23 percent of patients arriving at the emergency room test positive for HIV.

There is no way to measure the pain and suffering that AIDS has unleashed on this community. A few minutes ago, upstairs in this hospital, I visited with a 28-year-old man with AIDS named Jerry. Jerry used to be an intravenous drug user and was released from prison only 3 months ago. In that short time, he has lost 50 pounds, been stricken with blindness, and now lies comatose in his hospital bed. His mother Anna—who earns \$4 an hour as a factory worker in Puerto Rico—managed to come here to help her son. She comes everyday to help feed Jerry breakfast, lunch, and dinner. Anna is trying to save \$35 a week hoping she will have enough to take Jerry's body home to Puerto Rico for burial.

By the year 2000, the Bronx will have lost more lives to AIDS than all American soldiers killed in the Vietnam War. Today the Bronx has the highest per capita incidence of AIDS of any community in the United States. Among individuals here who are 25-44 years old, up to 20 percent of the males and 5 percent of the females probably carry the virus.

Ten percent of the Nation's total pediatric AIDS cases and 20 percent of all American adolescents with AIDS are here in the Bronx. Of the 50,000 intravenous drug users in this borough, half or more are HIV-infected. And yet, there are less than 7,000 drug treatment slots available.

Between now and 1993, New York City will confront a total bill for essential AIDS care services of over \$7 billion. Major hospitals in New York—both public and private—are now struggling, not just to provide care, but to stay afloat in a rising tide of unreimbursed expenses for services delivered to HIV-infected individuals who have no health insurance.

According to Federal law, hospitals which receive Federal aid may not turn away individuals who require emergency medical treatment—whether or not the patients have health insurance or can pay for their own medical treatment.

In reality, over the last decade, major changes in health financing policies have steadily eroded the economic incentives for delivering services to uninsured patients in greatest need.

Taking care of the sickest patients—those who arrive on the hospital doorstep through the emergency room—has become a losing proposition for the Nation's health care institutions.

For public hospitals, admitting and caring for a person with AIDS means losing an average of \$218 a day. In some States, the loss is \$386 a day.

The crisis is not someone else's problem. It is a problem for all of us, including the majority of Americans who do have health insurance, and who expect medical care to be there when they need it. More and more of the financial burden of caring for uninsured and underinsured patients is being shifted onto the medical bills and insurance premiums of those who are covered now.

Equally important, our misguided policies are eroding our ability to deliver care to people who need it, and making it harder for hospitals to do what society asks and expects of them.



According to a forthcoming nationwide audit of 275 private hospitals, 36 percent of these major institutions report that their patients sometimes must wait in the emergency room for at least 12 hours to be admitted to a hospital bed. Twenty-six percent of these hospitals reported that patients sometimes waited over 24 hours for a bed.

In a survey in New York City this year, nearly 30 percent of all patients in emergency rooms were waiting for a bed in the hospital.

Such situations are unacceptable. Hospital care in New York City or any other place in America should not have to be provided under battlefield conditions.

The AIDS and drug emergencies have made the need for reform even clearer. As we will hear today, the 1 to 1.5 million Americans with HIV disease are becoming the new "uninsurables." With the rapid spread of AIDS, a whole new class of Americans is emerging whose urgent health needs are largely unaddressed and unplanned for.

HIV is not a problem that will remain confined to New York and San Francisco. By 1991, 80 percent of new AIDS cases will be diagnosed in other cities.

Crisis also creates opportunity. Local communities, and institutions like this one, with their backs to the wall, are already taking innovative action. Bronx-Lebanon Hospital is stretching limited resources to deliver a full range of inpatient and outpatient services. But national leadership is required as well, because the looming bankruptcy of the health care system is a national problem, too. Congress and the President cannot just stand there, while the health care system collapses around us.

Nineteen-hundred and ninety is the year to act. We need to assure that every working American has health insurance on the job. Those who are unemployed should be entitled to participate in a public insurance program analogous to Medicaid. Senior citizens and the disabled deserve affordable protection against the cost of long-term care. No family in America should be condemned to poverty by the cost of long-term illness.

We must all deal more effectively with the AIDS epidemic.

We should create a million dollar emergency relief fund to help areas hardest hit by AIDS. Immediate additional funding is needed so that over-burdened hospitals, nursing homes, and other facilities can continue to function. If we can afford to bail-out the savings and loan system, we can find the far lesser sums needed to bail-out the AIDS care system too.

We need greater Federal support for the kind of comprehensive networks capable of delivering the full range of health and human services to deal with the AIDS epidemic, especially community-based outpatient home health care.

We must train and deploy more health and human services manpower to respond to the epidemic.

We must improve services for the homeless and those at risk for homelessness.

Finally, we should provide assistance to help disabled individuals pay the premiums for private health insurance.

At the very least, by acting wisely now—by finding the necessary resources and allocating them fairly—we can temper both the pain and cost of this national health disaster. And if we succeed in reaching our larger goal, we can deal with the other aspects of our health care crisis too, and make decent health care and long-term care accessible and affordable for all Americans.

We have a limited period of time. It isn't important to hear me out, but to listen to our witnesses. They have an important message to deliver.

Let me just mention to those that are here today the context in which we are holding this particular hearing. As someone who has been involved in the health care crisis for over 20 years in the U.S. Senate, has seen the health care crisis continue to grow, I think, we really are at a critical juncture, in terms of the health professions and those that are seeking health care services in the United States.

We see an expanding number of our fellow citizens who have no health insurance, 37 million Americans have no health insurance whatsoever; 24 million of those are hard-working Americans who work 40 hours a week, 52 weeks of the year, who want to be relieved from the anguish and the anxiety that they face should they themselves or their children become ill. You see the number of elderly people who have really been the backbone of our Nation, brought us through world wars and times of economic challenge, who now want to be able to live their senior years in peace and in dignity, either in their homes or in nursing homes. In the next 20 years, that number is going to increase three-fold if you're talking about individuals who are 85 years of age or older.

We find that many of our medical institutions are in crisis. We see that here at the Bronx-Lebanon Hospital. We know that is replicated in other hospitals in this city. We're going to see the closing of a number of the trauma units out in Los Angeles County tomorrow morning. We're going to see what is happening in rural America in St. Louis and in rural Georgia later in the week. And I think we're going to find out that there is a real crisis in the continuation of soaring costs and expenses, which has moved from about \$200 billion in 1980 to about \$600 billion now in 1989; 11.4 percent of our gross national product is being expended. We're spending more, getting less, and nowhere does it impact more than the children in our society. They're the ones who are really adversely impacted, whether it is the number of low birth weight babies that are being born, whether it's the expectant mothers, the 380,000 that are addicted and have no place to turn, whether it's the children who are not getting the vaccinations or getting the kinds of treatment that they deserve. They're a very important part of this whole health care crisis.

But the straw that could really break the back of the health care system is the impact of the twin epidemics of AIDS and drugs. These additional stresses on an already overburdened system, I think, really put our Nation in a very serious place in terms of our ability to provide basic and essential health care services.

You here at this hospital are doing an extraordinary job. I think we in the Senate have much to learn from you. We come here today to listen and to hear from those that have a story to tell. We



will not have all the time that we would like to spend, but we want to give the assurance—as Freddie has pointed out—we’re not unfamiliar with the health care crisis in this city. We have spent time in your hospitals, your medical clinics, and your nursing homes. We have spent time with your interns, with your nurses, with your patients, with your physicians, with those that are involved in the financing of the system. We will continue to do so. This has been an ongoing and continuing personal commitment, and I believe, of the overwhelming majority of American people.

As a member of the Senate, chairman of the Labor and Human Resources Committee, I am going to insist that our fellow colleagues in the U.S. Senate face the issue of access to health care one way or the other in this next session of Congress. Hopefully, we will do it in the kind of responsible, sensible way that those associated with the crisis here will later discuss. So it’s with that background that we bring our hearing to order.

We will start off with our first panel, individuals with HIV disease, Fernando, Jose, and Guy, and their social worker, Jossie Rigel. Then we have a second panel with Jerry Ernst and Dr. Lynn, and then Mayor-Elect Dinkins will make a final comment. That is the way that we will proceed. We look forward to hearing from our witnesses.

I want to say at the outset, and I think all of us are very mindful of how difficult it is to talk about personal illnesses. As one who comes from a family that has faced various medical challenges, in terms of a mentally retarded sister, a child that lost a leg to cancer, a chronic asthmatic, and other difficult health matters, I know very well health care challenges are something very personal. That is something that probably all Americans can respect. So I particularly appreciate our friends for being willing to share their experiences with us, so that hopefully we can, as a matter of public policy, be more sensitive and responsible. But I think we know how difficult it is, and I’m enormously and personally grateful to all of you for being with us here today. I want to thank all of you.

We won’t take the time to review the charts that are behind us, but I think for those that can read charts, the charts indicate some of the aspects we will be talking about. I won’t take away from the time. We need to hear from our witnesses.

Jose, we’ll start off with you, and we appreciate very much your being with us. Perhaps you will tell us a little bit about your experience, and we’ll have some questions for you.

#### STATEMENTS OF JOSE, FERNANDO, AND GUY, INDIVIDUALS WITH HIV DISEASE, ACCOMPANIED BY JOSSIE RIGEL, A SOCIAL WORKER

JOSE. First of all, it’s a pleasure to meet you, Senator. My name is Jose. I’m 38 years old. I’m a recovering drug addict and I am HIV-positive.

I was using drugs for 14 years. When I decided to stop using drugs in my life, in the last 7 months, when I was losing my center of gravitation, they told me to get the HIV test. I said, “For what?” I don’t need that because most of the time it’s very hard to get AIDS. That was my opinion.

When I found out I was HIV-positive, I was shocked. The first thing I was thinking was I'm dead. I was going to die. After the drug treatment center, I was sent to Bronx-Lebanon, and especially I owe part of my life to this lady sitting beside me, Jossie Rigel. She taught me how to deal with this disease. She told me you are a baby now, you have to start walking again. You have to get hope in life.

For me, there was no hope. I did not find out nothing. I said that's it, I'm dead, because when you decide you're going to stop using drugs for your own benefit, and the next step is a test because that was the way I was seeing it, I was going to die. It was too much to handle in one thing. It's having two problems in one: my drug addiction and my HIV disease.

I did not have no information at all. I didn't know what I was going to do. I was ready to go and start doing the best I know to do, using drugs. But with information I got in the hospital and then leaving, people like Jossie who told me, no, you've got hope. I started dealing with my life one step by one step, thanks to God, thanks to the good people who treat me. By now, what I'm doing is helping others in this hospital.

I'm a volunteer in this hospital. My director gave me permission to be here dealing with HIV patients. I really feel very warm about myself. I could say I'm proud of myself to stop using drugs. Being HIV-positive, I've had to take it to help other people.

We have the problems of any HIV person. We have some good supports in this program, the program I'm in. Jossie Rigel helped me a lot with the group support. She helped me, my mental spirits don't go down in my hope in my life.

I will tell you there's a lot of mistaken information about AIDS, especially in the Bronx. I see a lot of people dying in the street, shooting drugs because they think they are positive or they don't have enough information. We reach our community out in the street to tell them what is AIDS all about. AIDS is four letters, but the real information about AIDS, the issue to live or die, is too many people outside don't know they have AIDS or they are HIV-positive, and they—I couldn't tell you there's more people who don't find out, they deny to find out they are HIV, people who right now are in the position we are.

The CHAIRMAN. Let me ask you, you indicated that you're helping other people here in the hospital. How are you helping the other people?

JOSE. Giving hope. That's the best I can. Talk to them. If I see a person on my weekend pass from my program, I usually hang out with these people, and they told me—maybe one or two I explain to them to do something for your life. Here in the hospital, the best I can do is tell the people it's another day. Go to bed, pray to God, and tomorrow you will open your eyes with the same attitude. Don't think you're going to die, because you're not going to die from AIDS. I will die from something else, but I will live a hundred years being HIV-positive. [Applause.]

The CHAIRMAN. Tell me, how has your family reacted to all of this?

JOSE. At first, my wife supported me being HIV because the drug addiction I was on for 14 years. She knew that some day that will

happen. In my life with my daughter, I do not tell, at this moment to my daughter—she is 15 years old—that I am HIV-positive. But I have given information to her, try to go step by step because when we are in drug addiction we do a lot of damage to our families. And I did a lot of damage to my family.

The CHAIRMAN. Tell us a little bit about life out in the streets. For those that are addicted and those that may or may not know what their HIV status is.

JOSE. When a person is like I used to be, in the street for 7 days a week and 24 hours a day—maybe I remember one day to go back to my house. That was when I don't have no money and I was stinking for 3 or 4 days. We were eating from garbage cans because that was the type of drug user I was. I can tell you it's people in galleries in the city of New York, especially right here in the Bronx, who they don't have nobody to talk to them, to reach out and tell them, hey, here is this information. A piece of paper that says anything, something to put in their mind what the situation is we're passing through.

When I found out I was HIV-positive, I said, well, why, my God. Because I was 14 years using drugs in the street. Why now when I'm trying to do something decent for my did this have to happen? But I do have to expect something like that.

The CHAIRMAN. Those that are out in the street, do you think that if they knew help was available, they would seek help?

JOSE. No. Commercials on TV, maybe once in a blue moon in the newspaper, but that don't count. It's to go outside in the street, let the people know what the position of AIDS means.

The CHAIRMAN. You don't think many of those people would seek help if they could receive help?

JOSE. Yes. If they would be able to receive the help, they will. But they have no way in the situation to know what the deal is all about.

The CHAIRMAN. Is it generally felt out in the street that there isn't help available? What's generally the attitude?

JOSE. The attitude in the street is stay in the street. What are we going to do? We don't know.

Like I told you before, okay, they said it on TV. They say there's help lines. But when you call them, you get nothing.

The CHAIRMAN. OK. Fernando, would you tell us a little bit about your own story?

FERNANDO. Hello, everybody. My name is Fernando, and I am HIV-positive.

My story started like that. You know, I always think that I was a clean drug addict because I always used to work. I always used to have a home. But, you know, I was wrong.

When I found out that I was HIV, I went to the program. I was sick, so they sent me to the hospital. In the hospital, I told the doctor, you know, I wanted to do the test, the HIV test. So it came out positive. I was confused. I can never have AIDS, you know, because I thought I was clean. But I was wrong. It only takes one time to get HIV—to get AIDS.

I'm the youngest in my family of seven people. All my family are HIV. I got already three brothers died in Puerto Rico. One of my brothers is in the hospital, in Puerto Rico, dying right now. We



don't have the kind of medicine or service we need over there that we need for the patients.

I'm going to Puerto Rico. I'm going to Puerto Rico because over here on your own, I don't have no family. I always say to myself if I am going to die, I want to die over there with my family. Do you understand?

When I was in Puerto Rico, I found a Puerto Rican AIDS Foundation. A friend of mine referred me to Jossie Rigel, so she has been helping me a lot to understand, you know, what I got and what I have to do.

Right now, you know, I'm glad that I know what I got because now I know what I have to do for myself. The kind of treatment, I know it, and the kind of medicine I need for myself. Before I didn't know nothing, you know. I'm glad that I know what I got because there's people in the street that they don't know what they got. They are using heroin and cocaine in the street. If you ask them, they'll say, no, I can never have this. I can never have it. Maybe, you know, in the long run, they're going to the hospital real, real sick. Then it's going to be too late then.

Thank God that I know, you know, in time what I got because, right now, I take care of myself, and I found this lady over here, Jossie Rigel, because she's helping me a lot.

The CHAIRMAN. Tell me, Fernando, you have a family, too, as I understand.

FERNANDO. Yes, sir.

The CHAIRMAN. How did your family members react when you discussed this with them?

FERNANDO. When they know that I got it, that I was HIV, I was real afraid to tell my wife because, you know, I thought she was going to run away from me with my kids. But I was wrong. With the help that I got in the support group, you know, I explained to my wife what I got, and right now she's helping me. She's staying with me. I feel good and thank God for that.

The CHAIRMAN. Good. You talked a little bit about being a "clean dope addict." In terms of the galleries, what's the feeling of those that are out there? Do they think that they are going to escape AIDS? Do they think they're going to be the individual who isn't going to become infected? What's the feeling out there?

FERNANDO. In the street, like I say, you know, I used to always, you know, work, and, you know, have a place to go. I also used to go to those places, too, to get what I need, what I used to need for my body when I was sick. It's real—the street is real hard, you know. When you're doing those kinds of things, to get the money and do the things, you know.

But these people in the street, like me, you know, they came—they think they're never going to get AIDS. You tell them, listen, you're doing drugs, you're sharing needles and everything. You've got to go for the test. Do what you got to do. But they say, no, I know I don't have AIDS, I don't have nothing.

But they're wrong, you know. If they were to get real sick and go into the hospital, it's too late.

The CHAIRMAN. Thank you.

Guy, would you be good enough to tell us your story? I understand you're from Queens, actually.

GUY. Yes, that's right. My name is Guy. I'm from Queens. I'm 34 years old, and I've been doing intravenous drugs for about 16 years.

I got to a point in my life where I was tired of going up and down, losing jobs, getting jobs, you know, that roller coaster life. And I must have went to over a dozen treatment centers, and all of them were filled up. All of them said come back January, come back 1990. I needed help right then.

I came across one treatment center, Resurrection, the center I'm in right now, and they gave me the chance. It was probably the smallest of all the places I've been to, but it was the only place that said, OK, we'll give you that shot.

I was entered into the program, and I made a vow to get better, to live life on life's terms. And then about 4 weeks later, through a very understanding AIDS counselor that we have in this program, and our director, who urges the people to go for this test—you know, I'm really grateful to him also for that—I went and took the test. I found out I was HIV-positive, and it was like a bomb dropped on me. It was like, wow, here I am, I have two diseases now with no known cures. What do I do?

Then I had to think why I came there to begin with, you know? I said let me go for it. I had a lot of things to think about. Was my family going to treat me as an outcast? How are my friends going to think? What's going to happen? Then I realized it's all about me. It's all about me getting better, me getting well. And I won't be any good to anybody else if I'm no good to myself.

So my director, you know, he told me do whatever you have to do to keep your stress level down and go to support groups. That's when I had met Ms. Rigel, Jossie Rigel, and entered her support group, which has helped me a lot. It helped me a great deal.

I got a chance to become coordinator of this treatment center, and I got a view on the other side. Honestly, there's not enough beds for the amount of people that come into these centers. It's amazing. I would have to tell 20 people a day we have no room.

Now, as far as the AIDS thing goes, drug use and AIDS go together. For every 10 people that I see come into these treatment centers, I would put my heart into it that seven out of those 10 people are HIV-positive. When there are no beds—they go back to the galleries. When you're in a gallery getting high, you don't want to—you know, you don't care if you have a clean needle or not. You care about that shot. You care about that get-well fix. When you're there with that needle, the next person that needs that fix is going to take that needle. He may not have the money or want to take the time to go searching for a clean needle. So he goes back into that gallery, and then a new person will go into that gallery, and he'll pick up that needle he just used, and boom, there he goes. He's HIV-positive. It's going from one to one to the next guy.

These people really don't know about support groups. They don't have a chance to come into the hospitals like you did today and see what is the final stage of this disease. It's really scary. I'm scared, but I also have to remember that I have a drug addiction disease which will kill me even quicker than the HIV. And if I don't take care of my drug addiction, the HIV will get me. And I can't let either one overtake my feelings. I have to get better. I want, like I said, to live life on life's terms. And I also want to let other people



know what this is doing to them, you know? If it wasn't for people like the Bronx-Lebanon center for having the IV clinic and the support groups and just people that understand where you could dump on them and tell them, hey, I'm afraid today. You know, I don't want to die today. I want to live. People that you can cry to that you aren't going to feel they're saying under their breath, oh, you know, let's get away from this guy.

Not everybody knows about this disease. You can't catch it by sneezing on somebody. There are people that believe you're like a leper in the world because you have this disease, and that's not true. With proper care, vitamins, with proper knowledge, you know, stop using drugs—mostly to stop using drugs, proper, safe sex, things like that. These are all preventive ways to pass this disease on. And if it wasn't for the support groups, which are what show you—these are the places that teach you how to stay healthy with this disease and most of all how not to pass it on. Without these support groups, they're not going to learn.

Like I said, I thank my higher power for giving me resurrection and to have an understanding staff, counselor, and most important the Bronx-Lebanon and Jossie Rigel for teaching me the things that I need to learn about this disease to keep me living, to keep me alive, so I don't wind up on the fifth floor of Bronx-Lebanon half dead. That's what I want.

The CHAIRMAN. Thank you.

One of the points you mentioned, which is of great concern, is the fact that people are being turned away from residential drug rehabilitation programs is that really the situation as you understand it?

GUY. Yes. There's only so many beds. You know, if you have a treatment center that has a hundred beds and you have 200 people a day coming to this place, you know—our place, we try and call up other places, detoxes, hotlines, do everything they can. But there are so many drug addicts in all the boroughs of New York, in all of the United States. You know, there's really a lot of—an amazing amount of drug addicts. I see this firsthand.

Like I say, HIV and AIDS is the right-hand man to drug addiction. You are going to find out that one comes with the other. It's sad, hey, but that's the way it is.

The CHAIRMAN. Let me ask Jose, Fernando and Guy just a couple of other questions. After you leave the rehabilitation program, what happens to you with regard to housing, health care, and jobs? Are those difficult to get or to hold?

JOSE. Yes, it is very difficult because right now in my program, Reverend William is trying to work something out, and it's very possible for him to try to get an apartment for the person who graduates this Wednesday from the house. We don't have no—

The CHAIRMAN. Is that because they have AIDS or test HIV-positive?

JOSE. Regardless.

The CHAIRMAN. Regardless, you say.

JOSE. One of the drug addiction centers is getting the idea of having some difficulties to find a house for the person who don't have no family or place to go. It's very easy to graduate from the

program because we have the knowledge, and it's very hard when you have the knowledge and you don't have a place to go.

The CHAIRMAN. What about Fernando? Is it difficult to get through the program? I think that's a challenge enough. Then to try and get a job or get housing or get health care, are those difficult to get after you complete the program?

FERNANDO. Well, when I get out of the program, right now I have a place to live. There's a lot of people, you know, they have housing. It's real difficult for most people. They need more support.

The CHAIRMAN. OK. Well, I want to thank all of you very much. You've given us different aspects of this whole challenge in a very human way. I think Jossie probably if anyone ought to get a round of applause here, it should be her. [Applause.]

We want to thank the three of you and we want to thank Jossie for being an inspiration, not only to these individuals but to the rest of us as well. You really deserve a lot of credit, and we are grateful for your efforts.

Thank you all very, very much.

We'll move right along. We're honored to have the mayor join us for our second panel, and in conclusion, we'll ask the mayor to make whatever comments he might like.

We have on our next panel Dr. Jerry Ernst, who's the director of the AIDS program at Bronx-Lebanon Hospital, and Dr. Stephen Lynn, the director of emergency medicine at St. Luke's/Roosevelt Hospital and chair of the Task Force on Overcrowding for the American College of Emergency Physicians. Why don't you come forward?

Dr. Ernst, we're delighted to hear from you. I think you're well known, well respected not only here at this hospital and in the city but nationwide, for your imagination in trying to do more with less in a very challenging and difficult time in our whole health care system and dealing with both drug abuse and HIV disease. We have learned a great deal from you, and we very much appreciate hearing from you this afternoon.

#### STATEMENT OF JEROME ERNST, M.D., DIRECTOR OF AIDS SERVICES, BRONX-LEBANON HOSPITAL

Dr. ERNST. Thank you for those kind words, and thank you for letting me testify here today.

I know that I speak for my colleagues and my patients in recognizing the efforts you have been making in addressing the American Health Care Crisis. We here at Bronx-Lebanon are in the epicenter of the AIDS and drug epidemics. I think that the previous panel has eloquently testified to the problems that we face.

The rate of AIDS cases in the Bronx-Lebanon catchment area is more than 500 per 100,000 people. Over 20 percent of our inpatients and 15 percent of our outpatients test positive for antibodies to HIV. One out of every 11 babies born here tests positive. About half of these will become ill of AIDS. Almost 30 percent of men aged 20 to 35 that are hospitalized here for reasons that have nothing to do with AIDS test positive. So do 12 percent of the women in this age group.

Last year my team tended to 968 possible admissions with HIV disease. We had over 1,600 visits to our clinic. With our increasingly successful efforts as early detection and earlier treatment of asymptomatic seropositives, this number will dramatically increase. I feel that Bronx-Lebanon, an inner city hospital in a poverty-stricken area is doing an excellent job. Myron Strober, the chairman of the board of trustees, along with other board members, and the leadership of President Fuentes have been extremely supportive of our program from the start, and have succeeded in securing Federal, State, city and private support for the hospital's efforts.

We do not turn away AIDS cases, or any patient, regardless of their ability to pay. While other institutions fear damage to their images by caring for AIDS patients, as if caring for the sick could possibly damage a hospital's image, this hospital has reached out to needy patients and is constantly extending its limited resources to meet the challenge. It is our hope that the success of Bronx-Lebanon in addressing the problems of the needy can serve as a model for other hospitals throughout the Nation.

Governor Cuomo and his commissioner of health, Dr. Axelrod, selected us as a State-designated AIDS center and allowed us to open the inpatient unit you visited today. The enhanced reimbursement rate provided by the State has been of critical importance in developing our program of comprehensive services so that we can care for the HIV-infected individual from the first positive HIV test through the course of his illness.

Important to this comprehensive plan of health care is the outpatient area which you also visited. Dr. Stephen Joseph of the city's health department provided us with new quarters for our expanded clinic, and soon we will be open 5 days a week, providing care to children and adults with HIV disease. Counselors provided by the city and State will augment our prevention and education efforts. Our case managers will function in both the in- and out-patient settings. We will try to have the same doctor and case manager to follow the patient from the time of their entry into our system.

The hospital's State-supported rebuilding and revitalization program will provide new facilities for AIDS inpatient services and inpatient drug treatment programs. Ground will soon be broken for a 240-bed nursing home to be built across the street from here. Half of those beds will be for AIDS patients. I invite the Senator to return for those ground-breaking ceremonies.

Our just received \$3.7 million grant from NIAID for a community program for clinical research in AIDS will bring the newest treatment to our community. I thank the Senator for efforts in securing passage of that program. That center, combined with the community liaison program funded by the New York AIDS Consortium, will give substance to the complex network we have created of community health groups, local practitioners, neighborhood clinics, shelters for the homeless, dedicated housing, and drug treatment programs.

Our aim is to utilize the epidemic to unify the entire network of health care providers, train the community doctors to treat the early stages of the disease, provide the needed backing here at the hospital, and eventually accommodate those that need it in the nursing home.



Patients will move through the network as their needs demand, guided by the case manager. We hope to have an AIDS adult day-care program to provide a structured environment to the HIV patient, to keep him or her well, away from drugs, and as productive as possible.

There are some areas of immediate need. We need more doctors, nurses, and social workers. American-trained doctors must accept the responsibility of caring for their fellow citizens. This epidemic is the most important medical fact of the past and next decade. If we are lacking doctors, something is terribly wrong with our system of education.

I strongly support your efforts for the revitalization with the National Health Service Corps. We need to match providers to patients. We need more drug treatment programs. AIDS and drug abuse are linked to poverty. We have too much of that here. New York City has about a quarter of a million addicts but only 30,000 methadone treatment slots. There are yet no effective treatment programs for crack cocaine addicts, yet most of our AIDS cases here are drug abusers or people who have had sex with drug abusers.

Just last week, a State proposal to provide a network of primary care and drug treatment centers was turned down by HRSA. This hospital was part of that network. Services would have been provided to 10,000 people, and over 50 health care professionals would have been trained in HIV drug treatment primary care. Most of the projects HRSA chose to fund then were in areas with low incidence of AIDS cases. New York, with almost 60 percent of the country's AIDS cases, received only six percent of those funds.

We are an AIDS Drug Assistance Program, ADAP, center and are grateful for your support of that program. Yet that funding is not yet secure. We need more low-income housing. Allow me to dramatize the problem.

We have patients with CNV retinitis, a viral infection of the eye that results in blindness without daily injections of the HBG. We arrange with the visiting nurse service to make daily visits to administer the drug. But if the patient has no home, he or she stays in the hospital until one becomes available. Frequently, the patient dies in the hospital before all of these arrangements are completed.

HIV disease is now a chronic illness. We need help with the strengthening of our service networks so that we can reach everyone, educate and prevent infection of the uninfected, and treat early the HIV-positive person. We need Federal disaster relief. Our Government appropriated \$3.5 billion for San Francisco 8 days after that terrible earthquake that killed 60 people. Less than one percent of that amount, \$35 million has gone to AIDS in San Francisco, a disaster that has killed over 5,000 residents of that city.

Our community is in crisis. AIDS is just another blow. Crime, drug abuse, single-parent families, teenage pregnancy, poverty, all of these are endemic here. When one thinks of America, one does not think of the South Bronx. When one views the Government's response to our needs, one does not think of America. Surely we deserve better.

Thank you. [Applause.]

The CHAIRMAN. We'll come back to the questions. We'll hear from Dr. Lynn who will tell us about the crisis in the emergency rooms and about the general challenges of emergency medicine at St. Luke's/Roosevelt Hospital. He is also the chairman of the Overcrowding Task Force of the American College of Emergency Physicians. We look forward to hearing from you.

**STATEMENT OF STEPHEN LYNN, M.D., DIRECTOR OF EMERGENCY MEDICINE, ST. LUKE'S/ROOSEVELT HOSPITAL, AND CHAIRMAN, TASK FORCE ON OVERCROWDING, AMERICAN COLLEGE OF EMERGENCY PHYSICIANS**

Dr. LYNN. Senator Kennedy, Mayor-Elect Dinkins, and Borough President Ferrer, it is a great pleasure, indeed, to be able to speak to you. I am Stephen Lynn. I am an emergency physician. As you said, I'm director of the Department of Emergency Medicine at St. Luke's/Roosevelt Hospital Center, one of the city's largest hospitals. My staff and I see over 150,000 patients in our emergency department every year.

I speak to you, as well, as a representative of the American College of Emergency Physicians, a national organization representing 13,500 emergency physicians, and I'd like to think that I speak to you, as well, as an advocate for the 90 million patients who will enter emergency departments in this country in the year 1989.

Many Americans face a significant health care crisis that is widespread and growing. Hospital overcrowding and the resultant backup of patients that occurs in emergency departments throughout the country is severely limiting access to emergency care and has the potential to cut the quality of that care beyond the margin of safety.

Overcrowding occurs when there are no available inpatient beds or intensive care unit beds, or it occurs when neighboring hospitals have closed their doors or their emergency departments. As a result, patients who are admitted to the hospital by emergency physicians wait in the emergency department for inpatient beds. Some patients wait for hours; many patients wait for days.

I am aware of emergency departments in which more than 50 patients have been waiting in the emergency department, admitted, for inpatient beds. I am aware of patients that have waited longer than a week in the emergency department with no inpatient bed. And I am aware of many patients who have been admitted to the hospital and discharged from the same hospital, never having left the emergency department, never having seen an inpatient bed.

The essence of the problem is quite simple. There are too many patients accessing the health care system through the emergency department, and there are too few inpatient beds available.

If society thinks that this is a problem that only affects the poor or only affects inner city hospitals, it is wrong. It may be dead wrong. The American College of Emergency Physicians has recently completed a broad-brush survey in which physicians from 41 of its 50 chapters and the District of Columbia have reported severe overcrowding in their hospitals and emergency departments. Gridlock in the emergency department is reported in the entire Eastern seaboard: Washington, Baltimore, Philadelphia, New York, Boston



and Ontario. We have reports from Los Angeles and from San Francisco, from Miami, from Memphis, and from Houston. But we also have reports from Greenville, NC, and from Alaska, and from rural West Virginia.

What has caused this problem, Senator Kennedy? There are two causes. First, there are a shortage of resources. Second, there is a tremendous expansion in the need for emergency care. Shortage of resources. We have too few nurses. There are many beds available in this city and throughout the country today that cannot have patients in them because there are no nurses to staff them. Hospitals and emergency departments close. There are not enough nursing home beds.

In New York and in Massachusetts at this time, there are thousands of patients that occupy acute care hospital facilities that everybody agrees would be better served in nursing homes or in home health care facilities, but for whom no such services are available.

Next, there is an increased demand for emergency services. The American Hospital Association tells us that in this year 40 percent of all patients admitted to all hospitals in this country will be admitted through the emergency department. In 1980, that number was 30 percent. And as I mentioned before, they tell us that in this year, 1989, 90 million patients will seek care in this country's emergency departments, more than had ever done so before.

When we add to that the increased number of poor and/or uninsured patients, persons with AIDS, and patients with drug abuse, the system that is overcrowded and overwhelmed begins to crumble. AIDS may be the straw that breaks the camel's back.

Unfortunately, the results of overcrowding are well-known to most of us. That is part of why we are here today. Emergency departments were not intended to be inpatient units or intensive care units. And when they are asked to provide those services for a prolonged period of time, quality of care suffers and patients suffer. When half or more of the emergency department's staff and space and equipment are devoted to providing care for patients who are admitted to the hospital, how can we adequately provide care for the next patient that approaches the emergency department with a new illness or a new injury?

And, once again, if a hospital or an emergency department has no bed, whether the next patient who comes to that emergency department has no home and not a dollar in his pocket, or whether that next patient is capable of purchasing the hospital, if there is no bed available, that patient will wait. The emergency department is the great equalizer in our society.

Where do we go from here? We need to re-evaluate our most basic societal commitments and priorities, and we need to reinvest in our health care system. First, we must guarantee the access to primary, preventive, continuing and emergency care to all members of our society, and we must guarantee adequate reimbursement for hospitals, community clinics, and providers of that care. We must guarantee that health care once again becomes a right of all members of our society and not a privilege only for those few who can afford it. And until we do so, none of us can be confident

of access to quality of emergency care, quality of care that we expect and that we deserve.

Next, we must re-evaluate the way in which we pay for emergency care and make certain that there are no financial obstacles to that care. We must listen to the study commissioned by our own Health Care Financing Administration. And when that study asks in its title, "Prospective Payments to Hospitals: Should Emergency Admissions Have Higher Rates?" and when that study answers resoundingly yes, and says patients who are admitted through the emergency department cost more than patients admitted through other means, we need to take heed and we need to take action.

Particularly in New York City, but in other parts of the country as well, we must encourage the building of new hospitals, new emergency departments, and new critical care units. And we must be ready to reimburse for their full cost of construction.

Last, we must guarantee the highest quality of professional nursing staff is attracted and retained to work in our hospitals. Those thousands of beds in this city and throughout the country that are available today that could be providing patient care, but can't do so because of lack of nurses, must be put back in line.

Senator Kennedy, as we look to the future, we join your fervent hopes that peace and enhanced security will allow us to redouble our societal investments. The place is health care. The time is now. [Applause.]

The CHAIRMAN. Thank you very much, Doctor.

Let me start off, and I welcome any comments or questions by the mayor.

Dr. Lynn, you were talking about those that are admitted to the emergency room that don't get a bed. What happens to them? Emergency rooms are not equipped to deal with patients—basically, they're designed to deal with the trauma of a few hours perhaps and then have that patient move on. What does this do to both the quality of care and to the patients themselves as they are in there, as you described in some instances, several days without getting a bed?

Dr. LYNN. You're absolutely correct in saying that emergency departments were not designed nor equipped to provide long-term care. You and I and other patients have very simple expectations when we're admitted to the hospital. We expect privacy. We expect the ability to turn out the lights. We expect the ability to have visitors, to use the telephone, perhaps even to see a TV or to sleep on a comfortable mattress. Emergency departments cannot provide even that minimal care.

We provide the basis medical and nursing care that our patients need. We are not able to provide the amenities of care that they deserve.

The CHAIRMAN. Whether people get a bed or not, does that depend on their ability to pay and their insurance? Or is that something that is uniform?

Dr. LYNN. It's independent of their ability to pay. Once again, those of us that feel that this is a problem only for the poor are making a big mistake. When there are no beds available, it doesn't make any difference if you're rich or poor. You are likely to wait in the emergency department.

This is a problem that affects all classes. It affects many, many cities in areas throughout the entire country.

The CHAIRMAN. The principal cause for the entry of patients into the hospital through the emergency room, outside of the issue of AIDS and drug abuse, what phenomenon has caused that?

Dr. LYNN. I think there are several reasons. I think one is that people don't have insurance and don't have ability to pay. In that case, those patients' only access to the health care system is frequently the emergency department. That may not be correct or ideal, but it's frequently the case.

I think as well today the patients that we see in the emergency department and in hospitals in general are far sicker, far more complicated in their illnesses, than the patients that we dealt with 10 years ago. We are much more efficient in admitting only those patients who require hospital care, and, consequently, the patients that come in tend to be much sicker and have a greater likelihood of coming into the hospital through the emergency department.

But I cannot overemphasize the effect of poverty, AIDS, and drug abuse as adding substantially to increase the number of patients entering the health care system through the emergency department.

The CHAIRMAN. The next question, if we were facing a crisis in the emergency rooms before AIDS and drugs, which I understand from your earlier testimony we are, what has this additional burden placed on the emergency room? And if you would, can you extrapolate on your understanding of what will be the flow line of needs and demands of both AIDS and substance abuse over the next 5 to 10 years and what will be the repercussions on emergency rooms and hospitals?

Dr. LYNN. I think that unfortunately there are not going to be short-term or easy solutions for poverty, for AIDS, or for drug abuse. And even if we chose today to create thousands of additional nurses, it would take years for them to enter the system. And even if we chose today in New York City to build five or 10 new hospitals, it would take 5 years before they were occupiable.

I don't see any easy short-term solutions to the problem of hospital overcrowding and emergency backup. My grave concern is that in the near short-term future the problem that we have today and the problem that we face so significantly in New York City will be far more severe throughout the rest of the country. I fear the worst. I think we need active intervention at the present time.

I know that that will take effort. I know that that will cost money. I am convinced it needs to be done, and it needs to be done now.

The CHAIRMAN. Finally, what you are describing, is that the condition, or becoming the condition, in most of the emergency rooms in hospitals in New York City and in major urban areas of the country? Is that what you're telling us?

Dr. LYNN. The situation that I'm describing is the problem in almost every emergency department in New York City without exception. And it is frequently the problem in many emergency departments throughout the rest of the country. And our concern, as the American College of Emergency Physicians, is that the problem that we see today seems to be increasing in scope and scale and ex-



tending beyond the confines of the inner city into the suburbs and into the rural areas as poverty, AIDS, and drug abuse move out of the city as well.

The CHAIRMAN. Dr. Ernst, let me ask you, how many people with AIDS are in your hospital but do not need an acute bed?

Dr. ERNST. Probably around 10 percent of our patients are awaiting housing or awaiting a nursing home bed. The problem is particularly acute in patients with AIDS dementia. Probably five percent of our patients are demented with no place to go. State mental institutions will not take them, and nursing homes won't take AIDS patients and certainly won't take these patients. And it's very difficult to find housing, safe housing, for demented people. So we have a substantial number of demented patients.

We have a substantial number of patients who need hospice care. I mentioned to you earlier that the only hospice in the borough closed because reimbursement rates were not adequate to pay for the care. So we have people waiting to die in some of our beds who are getting care, but that care does not have to be given in an acute care hospital.

We have a substantial number of homeless patients. We do not discharge homeless AIDS patients back to the street or back to the shelters. So they frequently wait here until we are able, our social workers, our case managers are able, together with the city, to find them housing in the community—housing, I must add, that even for a healthy person would be very difficult to live in.

The CHAIRMAN. Tell me about the nursing homes. What is the situation? You have people that from a medical point of view could go to a nursing home if there were nursing home beds available, and that would actually cost the system a good deal less and perhaps be more humane for that individual, but they are not able to get placed in nursing homes?

Dr. ERNST. Well, there are one or two nursing homes in the city that accept AIDS patients. The other nursing homes do not accept AIDS patients. We are unable to place them in those nursing homes. That's a primary motivation for the hospital building a nursing home across the street that will accept up to 128 patients. We are actively working with Commissioner Axelrod in getting some AIDS programs in some borough nursing homes, but it's very difficult. It's very slow, and there are a lot of barriers, both societal barriers and also fiscal barriers.

Dr. LYNN. For nursing homes in general, Commissioner Axelrod and the New York State Department of Health recognize that the positive unmet bed need—that is, the number of nursing homes that New York City needs today—is 4,500 nursing home beds.

The CHAIRMAN. Just a final couple of questions, and then I'd ask the mayor to ask what questions he might have.

As I understand, this service area has five primary care doctors per 100,000 patients. The national average is 211 per 100,000. What can you do in the face of the shortage? And I also heard that you have places available for doctors that specialize in infectious diseases and also other trained personnel such as social workers. Could you talk about that?

Dr. ERNST. The major part of health care to these patients in our hospital is met by house staff. House staff from foreign countries

who come to America to learn the best America has to offer are shouldering the burden that American doctors are not picking up. So, first, we're doing an injustice to these highly motivated foreign-trained doctors who come here and forced to take jobs that American doctors won't take.

Attending physicians, people who have finished their training, we hire a substantial number of Bronx-Lebanon graduates, graduates of our training program. I have a pulmonary fellowship training program, and I try—my partner for 10 years is a graduate of that program. We try to hire people that we train because we know that we trained them well. It is very difficult for us to attract.

Dr. Irene Grant from Memorial Hospital is here. We have two positions open now that are paying—I'm ashamed to let her know this, but are paying close to \$100,000 for an ID physician. I am unable to fill those positions.

We are trying to hire nurse practitioners and PA's. We have one PA now. We're getting another PA. It's been a tremendous struggle to find these patients. Primary care doctors, good primary care doctors can deal with most of the problems of the AIDS epidemic. We envision the ID consultant, the super-specialist, to have a supervisory or consulting role in this apparatus, and the primary care doctor or the family practitioner will do most of the daily work. It's very difficult for us to find primary care practitioners and then find those who have the interest in AIDS care.

The situation is—

The CHAIRMAN. The National Health Service Corps, did you try that?

Dr. ERNST. We do not meet the requirements for health manpower. This district doesn't because there are so many doctors in this hospital with no patient care responsibilities that are counted in the number. So our pathologists and our radiologists, the providers who do not take care of patients but are necessary for the hospital's function, count in our total. We do not make it under that system.

The CHAIRMAN. We'll do everything we can in order to change that. Just a parenthetical, and then I'll yield.

The American taxpayer pays about 65 percent of all medical education. We used to, 15 years ago, have one out of three applicants—or of three applicants that were qualified in any medical school in the country, they had to choose one. The taxpayers pay, unlike law school. And who's paying those taxes are basically working Americans. They're the bulk of it, and they're the ones that are in the greatest need generally in terms of primary care. It always seemed to me that we fought that battle a number of years ago. Maybe we'll come back and try to win it this time. But if you're able to indicate to those young people at the start of it that they are going to have some advantage, they're academically and otherwise qualified to gain the entrance into medical school, why not give them some edge if they're willing to serve?

As I say, we debated that, and I ended up on the short end of the votes on that one some time ago. But you never know these days. We may come back to it because it is, it seems to me, a very, very special and important responsibility. Other countries are able to deal with that issue in a variety of different ways. We certainly



have to deal with it a great deal more effectively than we have to date.

I don't know whether the mayor would like to ask any questions. We've got two outstanding experts. I'm sure we've got a lot of experts in this room today, having spent just a few moments with many of them as we toured through the corridors and the facilities.

I'd be glad to yield to the mayor.

Mr. DINKINS. I have just one area of questions. You seemed certainly to have covered things very well. It's good to see you again. I'm glad you're here on this important topic. Always nice to be with my colleague on the Board of Estimate, Freddie Ferrer.

You discussed the shortage of beds and the difficulties that give us the backup we've got in emergency rooms, and with an awareness that many people use the emergency room as a family doctor anyhow, and thereby they don't come often. They come when they're in bad shape.

It's my understanding that often we have people in beds who have sufficiently recovered to be discharged, but the absence of availability of home health care is such that they do not get discharged, maybe 1 day, 2 days, 3 days, or 5 days at considerable cost and, obviously, no great advantage to the patient. I just wondered if you had any feel for that aspect of things.

Dr. LYNN. Early in 1989, the Department of Health released a survey in New York City that estimated that 6 percent of the city's acute care hospital beds were filled by patients that either required nursing home care or home health care. I know that in my hospital there is almost 10 percent of our acute care beds filled by patients that we call on an alternate level of care. Everybody agrees—the family, the physician, the patient—that that patient would be better served elsewhere, but the services and the facilities at the present time are not available.

If we were able to free up those beds, we would have far less problem in admitting patients through the emergency departments and finding beds for all types of patients throughout the city. It would be an important step in the direction of the solution to solve that problem. Massachusetts and other States have very similar problems.

Mr. DINKINS. The sad part about it is that those persons who do this home health care work are very low-paid people.

Dr. LYNN. Very low pay, indeed.

Mr. DINKINS. A tremendous turnover, in excess of 50 percent, poorly trained—it's not their fault; absence of knowledge about cultural differences, a variety of reasons. And it is such a small expenditure in a relative sense that would help cure that problem. Some of us have so argued for a long time.

Dr. LYNN. It would be a wise expenditure.

The CHAIRMAN. I couldn't agree more with the mayor. We all know in our society—take people, for example, in day care, nickels and dimes, Head Start programs, nickels and dimes, taking care of our children. People who are trying home health care, those who are looking out after our parents, don't get paid a decent wage.

It just seems to me it's another reflection of where we are as a society. I mean, somehow we've got to be serious about this busi-

ness to begin to come to grips with it. That's another issue for another time.

We were able to get \$20 million for home health care for people with AIDS in the budget this year. You could probably use it all up in the Bronx. Nonetheless, with scarce resources, we'll wait for the mayor's application for that.

You make a powerful, convincing case for the use of community-based outpatient services how to treat these people, how to do it in a humane and decent way to delivery care that is both cost effective and compassionate. We want you to know we will continue to support such initiatives.

I want to thank you very much. This has been a powerful presentation. I think it's been enormously informative. I had some sense about the problem before getting started this afternoon, and you have reaffirmed my sense of urgency in a very significant way. I must say, one thing that I found extraordinary rejuvenating is the presence of men and women like you in this hospital, in the thick of the gale and willing to undertake impossible and critical tasks. Hopefully, your efforts will inspire enough of those that have the responsibility to act, to be more responsive to health care needs and finally come to grips with this life or death issue.

We would now like to hear from Mayor-elect David Dinkins. He has, as many of you know, been a good friend of mine, and I welcomed the opportunity to work with him in the course of his campaign. One of the very important reasons is because of his long-standing commitment to quality health care, which is ongoing, persevering, and persisting. It is an issue which I certainly care a great deal about, and the people of New York City care a great deal about. It's important to have someone at the helm who has spent time on this issue. I think it can make a big difference.

I welcome whatever comments the good mayor would like to make at this point, and then I'll make a final few comments, and we'll wrap up our hearing.

Mayor, we're delighted to—I almost said, welcome you to New York. We are glad to be here and back in a familiar setting. We have spent time in New York hospitals before, and the mayor has been good enough to help educate me about some of the challenges the city faces in terms of the health care crisis.

#### STATEMENT OF DAVID DINKINS, MAYOR-ELECT, CITY OF NEW YORK, MANHATTAN BOROUGH PRESIDENT

Mr. DINKINS. Thank you very much. I'm sure you've acknowledge heretofore the presence of your colleague in the Congress formerly, Herman Badillo. I'm sure there are others here.

Freddie, I'm delighted to be here with you. They told me you were going to be up in his neighborhood, in Massachusetts, and I was delighted that you're here.

I do have just a few remarks. I thank you, Senator Kennedy, for permitting me to address this public hearing on a topic that symbolizes one of the worst public health disasters to impact on our Nation and our city in decades. That's HIV illness and AIDS. We have just heard the most compelling and vivid testimony from cou-

rageous, dignified people who are living with AIDS or helping those living with and affected by HIV and AIDS.

The fact is that we're all impacted by this epidemic every day, and I just want to say a word about these physicians. It makes you feel good about the future to know that there are young men and women who are dedicated and committed and who truly care and are out here working.

You know, I suppose there's nobody in this room that doesn't know somebody who now has AIDS or who has died from AIDS. I know I can number quite a few. And more and more, we're coming to recognize that it can strike anywhere and at any time. The time was when we felt that AIDS was an illness of white gay males. Well, we know it's not true. I don't know what the current figures are, but for persons of color, it's knocking on the door to 40, 45 percent, they tell me. So more and more, people like Freddie and I have to get word out in our communities and let people know that it is important. I was pleased to be supported, in the Board of Estimates, back away in getting money in the budget for AIDS education, not everybody thought it was that important at the time.

What should be perfectly clear is that in New York City we're fighting a dual epidemic: Drugs and AIDS. Our fight must be on both fronts. Current estimates show that as many as 90,000 drug-using males and 30,000 drug-using females are HIV infected. That represents fully 60 percent of an estimated total of 200,000 IV drug users in our city.

All recent studies indicate that HIV infection is spreading within the IV drug-using population of New York City. In fact, of those entering drug treatment programs, it is reported that about 60 percent are already HIV infected.

Senator Kennedy's plan is based on the understanding that the drugs and AIDS epidemic have not created a crisis but, rather, exposed a chronic weakness of our health care system. New York State has approximately 2.5 million New Yorkers without health insurance, and this figure is said to represent an under-count because they only include people that are not covered for the entire year, when many people have insurance for only part of the year.

And who are these people? Approximately 720,000 are children under the age of 18. One in every 5 children from low-income families is uninsured. New York City has nearly 1.4 million people who are uninsured. And of these 1.4 million, 23 percent are Latinos and 19 percent are African-American.

Sixty-six percent of the uninsured are employed or are dependents of an employed person. Many New Yorkers without health insurance have low incomes. One of every four persons with incomes below 200 percent of the poverty level—that is, \$24,200 for a family of four—is without health insurance.

I've said repeatedly that there is a clear connection between poverty, drug abuse, unemployment, homelessness, inadequate education, and discrimination. Among these, there is clearly a connection. The State Commissioner of Health, David Axelrod, has put forth a far-reaching comprehensive proposal for universal access to health care coverage for all New York State residents. This plan, called Unicare, emphasizes primary and preventive services with a system of cost containment through a single payer authority that



will collect bills—these are sole payer bills—and negotiate reimbursement rates.

This is a plan which should be supported while at the same time we fine tune its many parts to meet State and city needs. I intend to work closely with the State toward this goal.

We would certainly want to see priority given to the development of a national health plan and, with this in mind, will work closely with my friend, Senator Kennedy, to ensure the development of a proposal that would provide universal access for all Americans. Senator Kennedy's AIDS legislative agenda affords us a unique opportunity to support a proposal that covers the many critical aspects of the HIV/AIDS epidemic, targeting emergency relief to localities most severely impacted by AIDS, like right here in New York City; supporting community-based services which represent the front line of defense against AIDS; creating transitional and supportive housing for homeless people with AIDS as the most humane and cost-effective response; providing financial assistance to those individuals that are chronically disabled to maintain the health and social services they need to deal with AIDS and drugs; and a call to revitalize the National Health Services Corps and the VISTA program as a means of expanding the health and social services personnel needed to fight these dual epidemics.

I'd like, Senator, to see if you can't do something so that these physicians who don't really contribute to health care don't water down the formula so as to prohibit your ability to make application. That seemed to make a lot of sense to me.

I pledge to be a leading player in a city, State, and Federal effort to demand that New York City receive the necessary dollars to save lives, because no life is expendable. And I will work aggressively to join other leaders in those localities hardest hit by the epidemic so that we can be one voice in Washington.

We will go to Washington, and we will bring our Federal representatives to New York City so that they can also hear the voices of those represented here today.

Today's testimony clearly articulated the need. Our city and Nation is rich with the talent to combat drugs and AIDS and improve a failing health care system. I intend to work very hard in support of those initiatives like the Kennedy plan that will work for this city and improve lives.

Senator, I'm going to be in Washington tomorrow about drugs with Senator Biden. There is this connection between these things, especially in New York—drugs and AIDS.

I don't know. It is, on the one hand, awfully discouraging as we listen to the statistics and we hear about what Freddie and I have to do about the budget in our town. But it's equally clear that we can't just close our eyes like it's going to go away. It is a comfort, though, to see some folks who are still in the trenches, still working hard to try to get the job done.

Senator, I'm grateful to you, as always, for being the vanguard of a very, very important and significant effort. And with my colleague to my right assisting, guiding, and advising, we're going to continue the battle here and do what we can.

The CHAIRMAN. Well, thank you. [Applause.]

Both for your continued involvement and for your willingness to speak out on these important issues.

When we are back in session, I intend to introduce legislation that, first of all, would create an emergency relief fund to help areas hardest hit by AIDS. Immediate additional funding is needed so that overburdened hospitals, nursing homes, and other facilities can continue to function. If we can afford to bail out the savings and loan system, we can find far less those funds needed to bail out the AIDS care system also.

We know that New York has designated similar funds. We're doing that with regards to the war on drugs. There's no reason that we shouldn't do that with regard to the AIDS epidemic as well.

Second, greater Federal support for the kind of comprehensive network capable of delivering the full range of health and human services to deal with the AIDS epidemic, especially community-based outpatient home health care, this has been referred to time and again during the course of the afternoon by individuals who have a real understanding about this issue. We have attempted to address that with just the home care. We're going to deal with it, I believe, in a more comprehensive way. We're going to try to with legislation.

Third, we are going to train and deploy more health and human service manpower to respond to the epidemic.

We must improve the services for the homeless and those at risk for homelessness. We've got the expansion of the McKinney Act. Tragically, of all the legislative authorization, the health services title of that legislation got the least funding, probably because the homeless don't have political action committees. But, nonetheless, we're going to fashion and shape the kinds of care network which have been referred to here to the extent that we can in that legislation. Then we should provide the assistance to help the disabled individuals pay the premiums for the private health insurance. That's part of a broader approach, but one that I am fully committed to.

I think one of the issues which those who are involved in the whole AIDS effort should take some heart from, is the passage of the Americans with Disabilities Act. The protections against discrimination for people with AIDS and HIV infection clarified under section 504 of the Rehabilitation Act in terms of Federally resistant programs have been extended in a very significant and important way in the AID. This legislation has passed the Senate and will pass the House of Representatives as sure as I'm sitting here. It may, in many respects, be the most important legislation we pass in this Congress. In the areas of employment, public services and public accommodations including the health care system, those that have tested HIV-positive and are being discriminated against, will have a Federal law to protect their rights. I believe that is extremely important.

Although somewhat outside of the specific topic we are considering today, antidiscrimination protections, for people with HIV infection have been referred to as the urchin of our ability to control this epidemic. If people are going to lose their jobs and their homes, they may not seek the health care services they need. In

addition, many people with AIDS have been denied access to critically needed health care solely on the basis of their AIDS diagnosis. We must no longer allow this to occur. Those that are freeing themselves from drugs through successful completion of rehabilitation programs, who want to be mainstreamed in society, in terms of employment, housing, and other aspects of life, know that we have laid down the public policy on that question. And I think that that will be an extremely important piece of legislation in this Congress.

We had hoped to be able to have time for public comment. I always like to try to do that during this type of hearing, but as far as I'm concerned, as far as our record is concerned, hearing from those that we heard from today has been a very, very powerful and compelling experience. You, here in this hospital are living this crisis in so many different ways, perhaps you forget how important your contributions are—but I won't forget.

[Additional statements and material submitted for the record follow:]



CITIZENS COMMISSION ON AIDS  
for New York City and  
Northern New Jersey  
March 1989

## The Crisis in AIDS Care: A Call to Action

New York City is in crisis. Three interrelated medical and social problems--AIDS, drug abuse, and homelessness--threaten to overwhelm our health care and social service systems and cripple the city's status as the nation's center of finance, business, and culture.

AIDS has not created this crisis, but it has added a crushing blow to a health care and social welfare system already devastated by financial cutbacks and the problems of dealing with an increasingly sicker and poorer population. In its study of the impact of AIDS on New York's future, the Citizens Commission on AIDS has concluded:

**\* An emergency in health care and social services already exists and will worsen in the next few years.** The vast majority of AIDS cases are still on the horizon. The 18,000 cases of AIDS reported in New York City since 1981 represent a mere 10 percent of the number of people currently infected with the Human Immunodeficiency Virus in the city. If San Francisco General Hospital, the single largest provider of care in that city, were in New York City, it would rank twentieth among hospitals in the number of AIDS patients. As early diagnosis and therapies become clinically advisable, as many as 170,000 people who are HIV-infected but asymptomatic may seek treatment, further overwhelming the system.

**\* Despite the efforts of many committed individuals in government and the private sector, this crisis has been met with a "business-as-usual" attitude.** Governor Cuomo's recent statement on financing the long-awaited New York State Five-Year Plan ("Remind me next year at budget time") reinforces the prevailing misconception that the situation is under control. Yet the Governor's call to slash the state contribution to Medicaid funding by \$350 million may well result in a \$1 billion drain on the health care system, as federal and city matching funds decrease accordingly.

**\* There is a false sense of isolation from the crisis.** Most political leaders, as well as the public, appear to believe that the epidemic affects only those who have or are at high risk for AIDS.

**\* Everyone's access to health care is at stake.** If the city's hospitals and emergency rooms are filled, care for all patients will be rationed. In fact, rationing has already begun.

**\* New York City's standing as the center of finance and business is at stake.** If the health care system is any further strained, it will become harder and harder to

retain and recruit employees. The costs of doing business in the City will continue to escalate while the quality of life in all neighborhoods deteriorates.

\* The budget deficit in New York State presents real constraints; however, postponing action now will only lead to greater costs and suffering later on. The epidemic moves at its own pace; it pays no heed to the fiscal year.

\* Several major agencies or task forces, including the New York City and New York State Departments of Health, have warned that an emergency exists and that future needs will be enormous; yet so far no correspondingly bold action has resulted.

\*New York City and New York State must forge a new spirit and new mechanisms of collaboration.

\*The federal government and the private sector must accept their responsibilities in the crisis. The federal government stepped in to rescue the savings and loan industry from fiscal mismanagement, even though the problem was largely confined to the Southwest. The federal government should treat the health of New York's citizens as a matter of national concern, not merely as a local problem.

\* New York City and New Jersey share many problems and even some of the same patients, and they should begin to implement regional coordination and planning. The Citizens Commission will issue a separate action plan for New Jersey in the near future.

## A BROAD PLAN FOR ACTION

The Citizens Commission on AIDS believes that the emergency has been amply documented and that the time for action is long overdue. The Commission recommends:

1. A **small, high-level body** made up of key public officials and private sector leaders in New York City and New York State should be created to oversee joint mobilization and coordination of effort. The body should be small enough to act quickly and should have the power to take needed action. This group should be guided by the principles that persons with AIDS and HIV infections are full members of the New York "family" and that New York will lead the nation in providing innovative, cost-effective, humane models of care. **TIMETABLE: 3 months.**

2. Now that New York State has issued its strategic plan, a joint City-State action plan should be negotiated, with specific goals, timetables, and financing streams. TIMETABLE: 6 months

3. In this action plan, immediate priority must be given to the creation and staffing of sufficient hospital beds to meet projected needs for all patients.

TIMETABLE: Immediate start, clear progress by one year, completion within two years.

4. Hospital bed shortages are only the most visible part of the crisis. Equal priority must be given to the creation of out-of-hospital alternatives (home care, nursing home beds, hospices, long-term care facilities, residential settings) and the support of community-based organizations that provide social services to Persons with AIDS and HIV infection. TIMETABLE: Immediate start, clear progress by one year, completion within two years.

5. Drug treatment and targeted AIDS education for drug users and their sexual partners (previously identified by the Commission as an action of the highest priority) should be provided on demand. TIMETABLE: Immediate start, clear progress by one year, completion within 2 years.



## RECOMMENDATIONS FOR ACTIONS IN SPECIFIC AREAS

These are the Commission's recommendations for specific action in major areas:

### A. HOSPITAL CARE

1. New York State should update its medical care facility plan to take account of the pressures on hospital beds caused by AIDS, substance abuse, and psychiatric admissions. This plan should incorporate at a minimum the state's own projections, which indicate that 2,200 additional beds, beyond the 1,800 currently used for AIDS patients, will be needed by 1994 for AIDS alone, even if substance abuse and psychiatric admissions do not increase. The plan should describe specifically how and where new beds will be provided. TIMETABLE: 6 months.

2. New York State should expedite procedures to recertify a number of beds taken out of service in the last few years and should prepare to expand capacity in New York City by adding new beds now, before shortages create a full-blown emergency. Optimistic projections of declining lengths of stay or decreased hospital use which may not materialize should not be relied upon to produce needed beds.

3. Programs to expedite training, recruitment, and retention of health care workers to staff hospital beds, especially in minority communities, should be developed immediately. "Bridge" programs can be developed to prevent dropouts in nursing schools, colleges, and high schools. Services such as day care centers and financial support for staff members with dependent children should be introduced. Housing for nursing and other staff is an especially critical need.

### B. LONG-TERM CARE

AIDS is a chronic, progressive condition punctuated by episodes of acute illness. Median survival with AIDS is more than one year and continues to lengthen but the incidence of disabling dementia is on the rise. All these combine to create an enormous, urgent, and largely unmet need for long-term care.

1. Home health care, a labor-intensive but relatively inexpensive form of care, should be expanded and improved. In order to receive home care, a patient needs a home. Home care workers should be given supports such as escort services, technical support, better supervision, and assistance with patient compliance, when delivering care to active drug users. Innovative recruitment programs should be created to hire and train home health aides in the communities hardest hit by the epidemic, and all home

care workers should be fairly paid for their work. We support the State's call for an AIDS Corps Program.

2. Because nursing home beds for PWAs are virtually nonexistent in New York City, New York State's enhanced reimbursement policies for nursing homes should be developed, and capital financing must be made available. Nursing home operators should be strongly encouraged to participate, and should receive help in educating staff, establishing liaisons with hospitals, and other technical assistance.

3. The quality of care in nursing homes for AIDS patients must be monitored and standards strictly enforced to prevent these institutions from becoming mere shelters with minimal services. Excessive use of psychoactive medications, especially where dementia is involved, must be avoided. AIDS patients in nursing homes need to be provided frequent access to physicians and access to AZT and other medications, including experimental drugs and clinical trials.

4. AIDS patients in nursing homes must have the option to freely choose rehabilitative or palliative care.

### C. COMMUNITY-BASED ORGANIZATIONS (CBOs)

Community-based alternatives to hospital care are more flexible, more patient-oriented, less expensive (although not cheap), and provide a means of relieving unnecessary hospital stays. CBOs are also the main source of the array of social services that PWAs and their families need. Unless they are given additional resources and support, however, CBOs cannot provide appropriate quality of care now or in the future.

1. Political and community leaders, especially religious leaders, should make the development of community-based services a highest priority among their constituents.

2. City and state agencies should increase funding for CBOs to enable them to provide care as well as prevention and education services.

3. Private sector funding should support CBOs, particularly in areas where public funding is difficult to obtain. Typical examples are Core Operating expenses, planning, and fundraising costs, which are hard to fund, but crucial.

4. Innovative programs to develop paid employment opportunities and volunteers for CBOs to enhance their ability to provide care in minority communities should be developed. Private funding could support some of these programs.

#### D. HOUSING AND HOMELESSNESS

Housing is the single greatest nonmedical need of persons with AIDS and HIV infection. Existing plans do not adequately address this need. As they become ill, more and more people will be unable to work, unable to pay rent, and at risk of homelessness. Many of the poorest people with AIDS are already living in marginal housing, or are homeless.

1. New York City and New York State should amend requirements that restrict immediate access to housing to people with CDC-defined AIDS. Expanded eligibility criteria would allow people with HIV-related illnesses and others who are asymptomatic but with prognostic signs of impending illness to obtain housing (not congregate shelters). This would enhance their health and protect others in shelters from HIV-related infections such as pneumonia and tuberculosis. Rent subsidies to prevent homelessness, now available to people with AIDS, should be continued and expanded to include medically needy people with HIV infection.

2. Governmental agencies should expedite the applications of CBOs willing and able to organize residential facilities.

3. New York State law should be changed to allow those who share living quarters with people with AIDS but who are not legally defined "family" members to continue to reside in these settings after the death of a PWA. Eviction of these people, many of whom are ill themselves, contributes to homelessness.

4. The "one-percent solution" should be adopted, that is, one percent of the approximately 300,000 habitable apartments owned, subsidized or controlled by the City should be set aside, as they become vacant over the next three years, to provide supported housing for homeless people with HIV-related illness. An additional set-aside should be established in new private residential buildings.

5. Minimum standards should be established in residential programs for persons with HIV-related illnesses. These should limit the number of people in any residence to a maximum of 50 and should provide private bathrooms, common dining facilities, and medical and social support services.



## **E. WOMEN, CHILDREN, AND ADOLESCENTS**

Women with AIDS in New York City are a rapidly growing segment of the population, moreover, they die more rapidly than men with similar diagnoses. In addition, New York City leads the nation in the number of children (birth to 13 years) with AIDS. The vast majority are from poor, minority families. HIV infection is also growing among adolescents as a result of drug use and sexual behavior, with young women affected in almost the same numbers as young men. Beyond the growing numbers of infected and at-risk youngsters, an estimated 10,000 children will be orphaned by AIDS within the next few years. An additional 50,000 to 60,000 will lose one parent.

1. The broad and specialized needs of women, including but not limited to reproductive counseling, should be reflected in service provision.
2. New York City and New York State should work together to provide access to primary medical care for children with AIDS or HIV infection, with an emphasis on early diagnosis and intervention and continuity of comprehensive care.
3. Transitional and permanent housing for children and their families and for homeless adolescents are especially urgent needs.
4. Day care facilities should be expanded for children who are too ill or developmentally disabled to attend regular day care programs.
5. Special services should be developed for uninfected children whose parents or siblings are ill with AIDS or HIV infection, and immediate planning should begin to provide for the children who will be orphaned by AIDS.

## **F. DISCRIMINATION BY CARE PROVIDERS**

People with or perceived as having AIDS or HIV infection are protected from discrimination by care providers under federal, state, and city laws. However, reported cases of discrimination, as well as surveys of health care professionals, reveal serious obstacles to the provision of effective and compassionate services.

1. Federal, state, and city human rights enforcement agencies should be appropriately managed, funded, and staffed to permit prompt and thorough investigations and prosecutions of discrimination complaints.

2. As recommended in the New York State Five-Year Plan, New York State should pass legislation defining the offices of individual medical practitioners as "public accommodations" under the human rights laws.

3. The human rights laws should be vigorously applied to long-term care facilities.

4. All health care and social service agencies should provide continuous and scientifically rigorous education to their employees on the needs of people with AIDS and HIV infection and on the use of "universal precautions" to prevent occupational exposure to HIV. Health care facilities must provide workers with sufficient protective equipment to ensure that precautions are routinely followed.

## **G. EARLY DIAGNOSIS AND TREATMENT**

Clinical practice patterns currently are shifting to earlier diagnosis and treatment of HIV disease. Although the efficacy of early anti-viral therapy has not yet been established, large numbers of middle-class gay men with private physicians are already receiving treatment in the asymptomatic phase of HIV disease. National clinical trials are underway to test the efficacy of early anti-viral therapy, and it is possible that release of new evidence may result in a surge in demand for services far beyond any presently envisioned. The trend for early diagnosis and treatment challenges society's commitment to equal access to health care.

1. The proposed joint city-state action plan should take account of changing clinical practice and the opportunity to provide benefits to HIV-seropositive people.

2. Voluntary, confidential or anonymous HIV antibody testing should be made more widely available; a wide range of medical and social services should be in place for referrals for seropositive people.

3. Access to primary care should be enhanced by increasing the very low Medicaid reimbursement rates to physicians and by enriching the ambulatory care system in poor communities. To the extent possible, this should be accomplished through the expansion and development of existing ambulatory care networks rather than creation of new HIV-specific facilities. The chief drawback of the latter approach is that it allows many health care practitioners to avoid responsibility for the care of HIV-infected patients by referring them to specialized centers. Community-based physicians should treat HIV-positive patients; continuing medical education should be provided to bring their knowledge and skills up to date.

4. Because there is a limited "window of opportunity" for effective early intervention in HIV disease, planning for its implementation should begin immediately. The majority of infected individuals are approaching the symptomatic phase of illness.

### **The Cost of Care**

How much will all this cost? The New York City plan does not give cost estimates or funding sources; the New York State plan reportedly included some estimates, but there were none in the final document. The New York City AIDS Task Force will report on March 22 on its costs assessment.

The Citizens Commission has estimated that approximately \$1.2 billion will be needed for patient care in fiscal year 1990-91. The State's share would be approximately \$216 million; the City's share approximately \$189 million; the federal government's share \$309 million; and the private sector's share (mainly insurance reimbursements) would be \$274 million. An additional \$165 million would come from such diverse and overlapping sources as Worker's Compensation and veteran's benefits. The annual cost would reach approximately \$1.9 billion in fiscal 1993-94.

Because these costs are only estimates, the Commission recommends:

1. New York City and New York State should provide specific plans on how the care and service needs of people with AIDS and HIV infection will be financed. These plans should include a contingency plan should federal funds not be forthcoming.

2. Private health insurers should make their benefits packages as flexible as possible, to allow reimbursement for out-of-hospital charges such as home care and other subacute care services.

3. Because many people who have private insurance lose it when they are unable to work, state agencies should develop, in cooperation with private insurers, a plan to subsidize private health insurance for individuals in this category. New York State already has a limited version of this plan. It should be expanded and financed by contributions from both government and insurers. It will provide more flexibility for the patient, and reduce the burden on the municipal hospitals.

4. City and state officials, as well as private sector leaders, should vigorously advocate increased federal funding for care needs. This should be a priority for all elected federal officials.



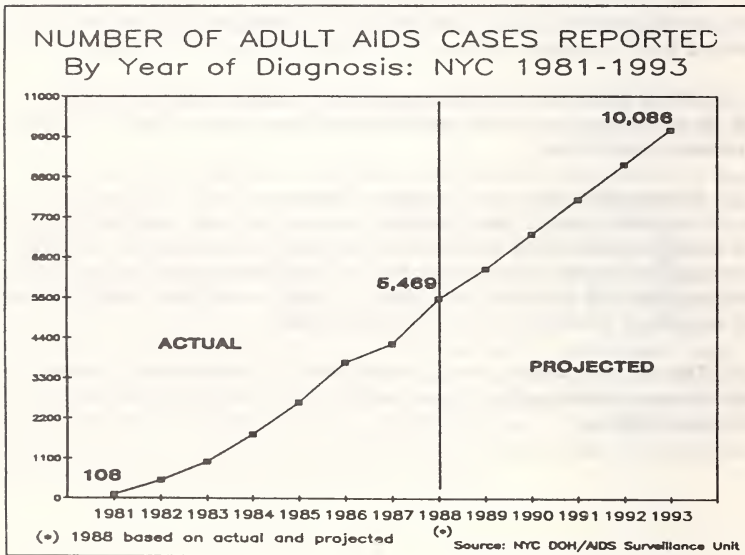
# AIDS: The Challenge Facing the HHC System

## RISE OF AIDS IN NEW YORK CITY AND NYC HOSPITALS

### THE INCIDENCE OF AIDS IN NEW YORK CITY IS GROWING RAPIDLY

AIDS cases in New York City have been documented by the New York City Department of Health (NYC DOH) since 1979. Growth in the number of adult cases has been fairly constant since 1981.

- The cumulative number of adult AIDS cases reported as of June 1989 in New York City is 20,254, according to the most recent NYC DOH AIDS Surveillance Unit Report. Of that number, 11,905 (59%) are known to have died.
- The NYCDOH estimates that the number of new AIDS cases diagnosed each year will almost double from 5,469 in 1988 to over 10,000 in 1993.
- The cumulative number of AIDS cases diagnosed in NYC is expected to reach more than 60,000 by the end of 1993.



NEW YORK CITY  
HEALTH AND HOSPITALS  
CORPORATION

Office of  
Strategic Planning  
August 1, 1989

## THE USE OF HOSPITALS BY AIDS PATIENTS IS GROWING

Not only are the number of people with AIDS growing, so is their use of NYC hospitals. Between 1986 and 1988 hospital utilization by adult AIDS patients increased as follows:

	<u>1986</u>	<u>1987</u>	<u>1988</u>	<u>1986-88</u> <u>Increase</u>
Adult Discharges	10,319	14,687	18,679	81.0%
Total Patient Days	219,394	316,866	404,120	84.2%
ALOS	21.3	21.6	21.6	1.4%

**Long stay cases (those with total patient days over 30 days) play an important role in hospital use by AIDS patients:**

- Long stay cases comprised 18.4% of total adult cases in 1988. Long stay days (those over 30 days), however, comprised 28.9% of total days.
- While long stay cases are growing at the same rate as all cases (80.7% vs. 81.0% from 1986 to 1988), long stay days are growing far more quickly than total days (108.9% vs. 84.2%).

**If every AIDS patient could be discharged after 30 days:**

- AIDS ALOS would fall from 21.6 to 15.4 days.
- Virtually all differences observed in ALOS (e.g., by payor, auspice) would disappear.
- Some 356 additional acute beds could be made available.

The majority of all AIDS hospital discharges (89.3%) reported in 1988 were in medical/surgical services.\* However, AIDS discharges constituted a small proportion of all medical/surgical discharges (2.8%), while AIDS days constituted 5.4% of med/surg days.

\* A better measure would be medical services only, but data from the State on certified capacity combines these services.

## SUBSTANTIAL NEW RESOURCES WILL BE NEEDED TO CARE FOR AIDS PATIENTS IN THE FUTURE

A citywide total of 4,990 acute inpatient beds will be needed for people with AIDS by December 1993 according to a recent forecast by the New York City HSA AIDS Task Force.\*

- In January 1989, 1,740 AIDS and suspected AIDS patients were hospitalized in New York City voluntary and municipal hospitals. The NYC AIDS Task Force bed need forecast thus suggests the need for an additional 3,250 AIDS beds by 1993, the equivalent of 6-7 new hospitals of 500 beds each.

The growth in AIDS will also increase the need for alternatives to acute hospital care.

- The NYC HSA AIDS Task Force projects the need for at least 2,640 housing units, 590 health-related facility beds, and 630 skilled nursing home beds by the end of 1993. If available, these would reduce the need for acute beds from 4,990 to 4,020.
- The NYC HSA AIDS Task Force also projected the need for almost one million physician visits\*\*.

---

### PROJECTED RESOURCE NEED FOR TREATING AIDS PATIENTS

	<u>1989 CURRENT</u>	<u>DEC. 1993 PROJECTED</u>	<u>ADDITIONAL NEED</u>
ACUTE BEDS	1,740	***4,020	2,280
HRF BEDS	0	590	590
SNF BEDS	128	630	502
HOUSING (UNITS)	**** 64	2,640	2,576
PHYSICIAN VISITS	?	** 1,003,620	?

SOURCE: NYC HSA AIDS TASK FORCE

---

\* This forecast will be revised based on more recent prevalence forecasts.

\*\* New CDC guidelines regarding anti-pneumocystis prophylaxis in HIV infected persons with a T-cell blood count below certain standards will increase the amount of required physician services in the future. Ambulatory projections will be revised to account for these new recommendations.

\*\*\* Assumes non-acute resources are available.

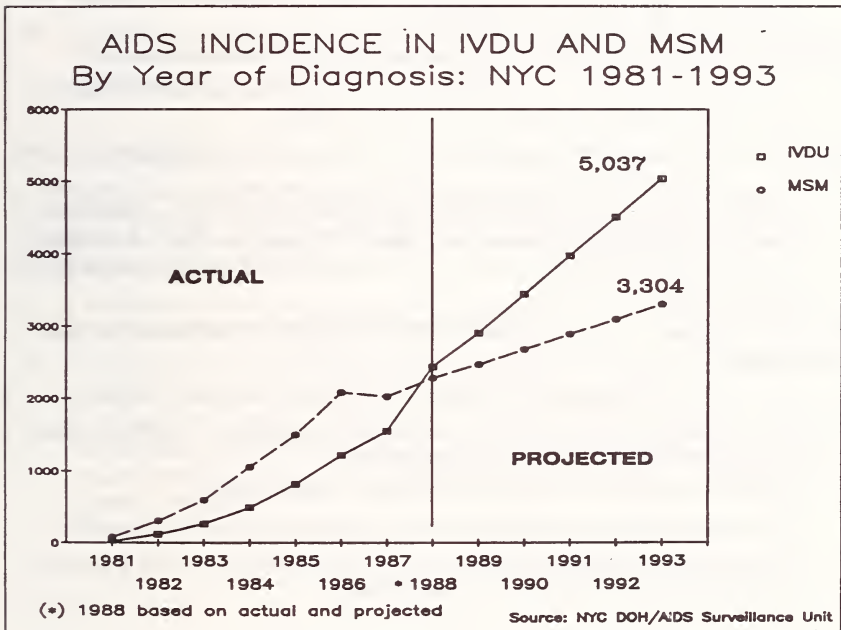
\*\*\*\* Excludes 522 SRO units currently occupied by persons with AIDS (as of 5/89)



## THE INCIDENCE OF AIDS IN NYC IS SHIFTING FROM MSM TO IVDUs:

AIDS incidence is growing more quickly among intravenous drug users (IVDUs) than it is among men who have sex with men (MSM):

- In 1988, for the first time, more new AIDS cases were reported among IVDUs than among MSM (43.4% vs. 43.2%).
- From June to December of 1988 MSM fell from 57.9% to 51.4% of all reported cases to date. IVDUs rose from 32.7% to 34.3%.
- By 1993 IVDUs will increase to 50% of all new AIDS cases. MSM will contribute 33%. The remaining 17% can be attributed to sex partners of IVDUs, blood transfusions, and other causes.



## **THE SHIFT OF AIDS INCIDENCE TO IVDUs HAS IMPORTANT IMPLICATIONS FOR THE FUTURE**

### **The population at risk is large :**

- There are an estimated 200,000 IVDUs in New York City and 60% are estimated to be HIV infected. Only approximately 35,000 of the estimated 200,000 IVDUs are currently enrolled in drug treatment programs in NYC.

### **AIDS will increasingly affect women and children:**

- The majority of pediatric AIDS cases arise from infection passed from mother to infant.
- Among the 200,000 estimated IVDUs, there are approximately 60,000 female IVDUs of childbearing age.
- Females, infected as IVDUs or as partners of infected men, will account for an increasing share of new AIDS cases as well; NYC DOH projects an increase in share from 16% in 1988 to 21% in 1993.

### **AIDS will increasingly affect low income and minority communities:**

- Low income and minority communities have been disproportionately affected by drug problems that place people at risk for HIV infection.

### **AIDS will increasingly shift from Manhattan to the outer boroughs:**

- The growth of AIDS will begin to shift from Manhattan which currently has 41% of all new cases, to Brooklyn, the Bronx, and Queens. By 1993, it is projected that Manhattan's share of new cases will decrease by 5%, Brooklyn's share will increase by 2%, and the proportion of new cases accounted for by other boroughs will increase by 1%.

### **These shifts suggest changes in the location and type of health services that will be needed:**

- Drug treatment programs must be made available for all who want treatment.
- HIV education, prevention, testing, counseling, and primary care treatment must be made accessible to low income communities.
- These services must increasingly be targeted to outer boroughs.
- These services must be integrated with drug treatment and prenatal programs.
- There will be an increased need among the IVDU population for long term care, housing, child care, foster care and social services.

## **A FEW NYC HOSPITALS HAVE ASSUMED DISPROPORTIONATE RESPONSIBILITY FOR TREATING AIDS PATIENTS**

While AIDS has contributed to increases in hospital utilization in NYC, not all NYC hospitals have been affected equally.

### **High Volume Providers:**

The top 20 AIDS providers, representing 45.2% of NYC's med/surg capacity, treated 74.8% of the adult AIDS caseload.

- Among these hospitals, AIDS patients filled an average of 8.2% of med/surg beds, contrasted with 2.2% among all other hospitals.
- Their AIDS caseload was 4.6% of their total med/surg caseload compared to 1.2% for all other hospitals providing AIDS care.
- The top 20 AIDS providers include 12 voluntary hospitals and 8 municipal hospitals. Thirteen are located in Manhattan, five are in the Bronx, and two are in Brooklyn.

### **Low Volume Providers:**

In contrast, the bottom 20 hospitals (low volume AIDS providers) represented 14.9% of the city's med/surg capacity but treated only 2.3% of the citywide AIDS caseload:

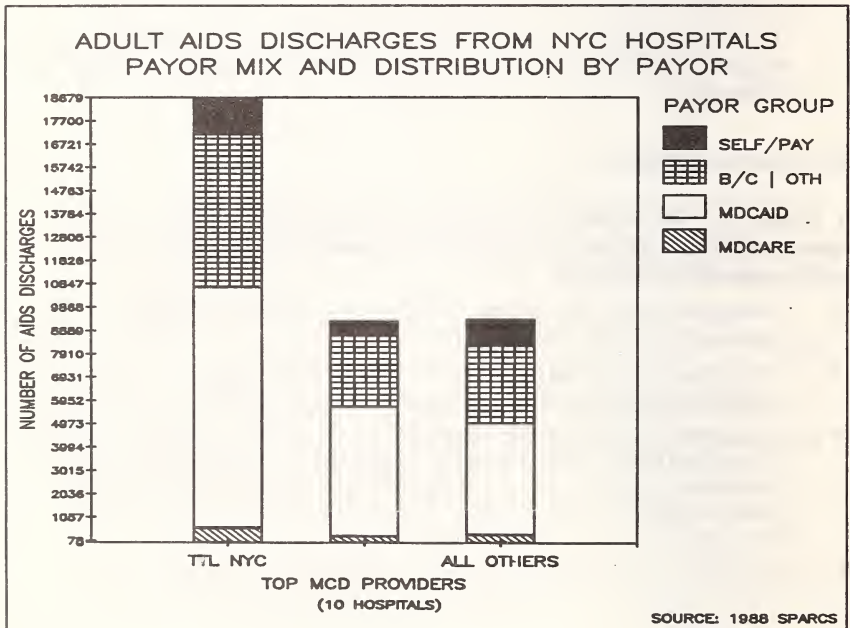
- Among the bottom 20 providers, AIDS patients filled an average of 0.7% of all med/surg beds compared to 5.7% of all other providers.
- Their total AIDS discharges were 0.4% of their total med/surg discharges while 3.2% of med/surg cases among the other hospitals were AIDS.
- The bottom 20 AIDS providers tend to be smaller facilities. With the exception of one State facility, all are voluntary and proprietary in auspices. Two-thirds are non-teaching hospitals; two are specialty hospitals; and most are located in the outer boroughs.



## EVEN FEWER PROVIDERS HAVE ASSUMED RESPONSIBILITY FOR TREATING MEDICAID AIDS PATIENTS

Ten hospitals provided care to 54% of all NYC AIDS discharges with Medicaid coverage in 1988.

- Five of these hospitals are HHC hospitals and five are voluntary facilities.
- Seven are located in Manhattan, two in Brooklyn, and one in the Bronx.
- Hospitals identified as low volume AIDS providers served less than 3% of all Medicaid AIDS cases.

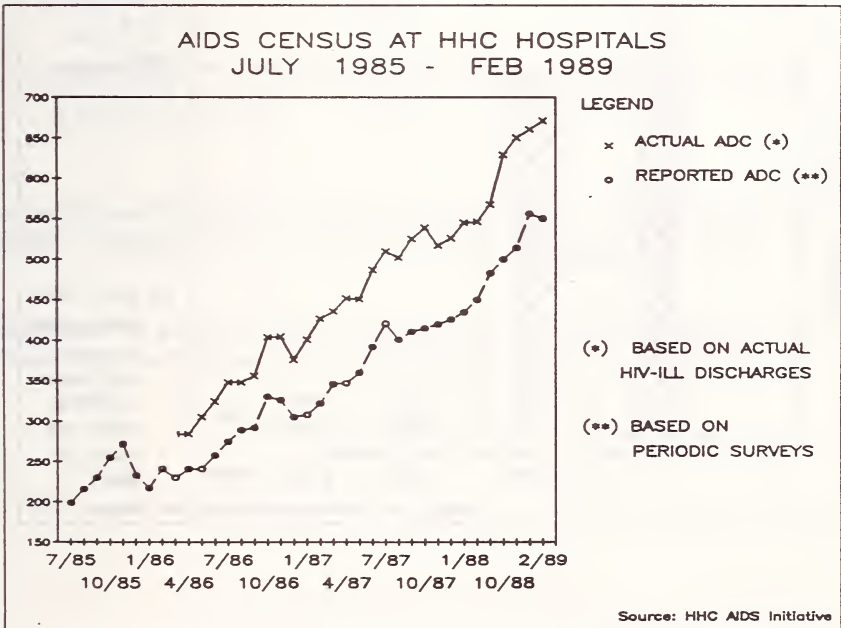


## HHC'S ROLE IN PROVIDING AIDS CARE IN NYC

### AIDS PATIENTS HAVE GROWN RAPIDLY IN HHC HOSPITALS

The growth in HHC's AIDS cases has paralleled the growth in the city's AIDS population.

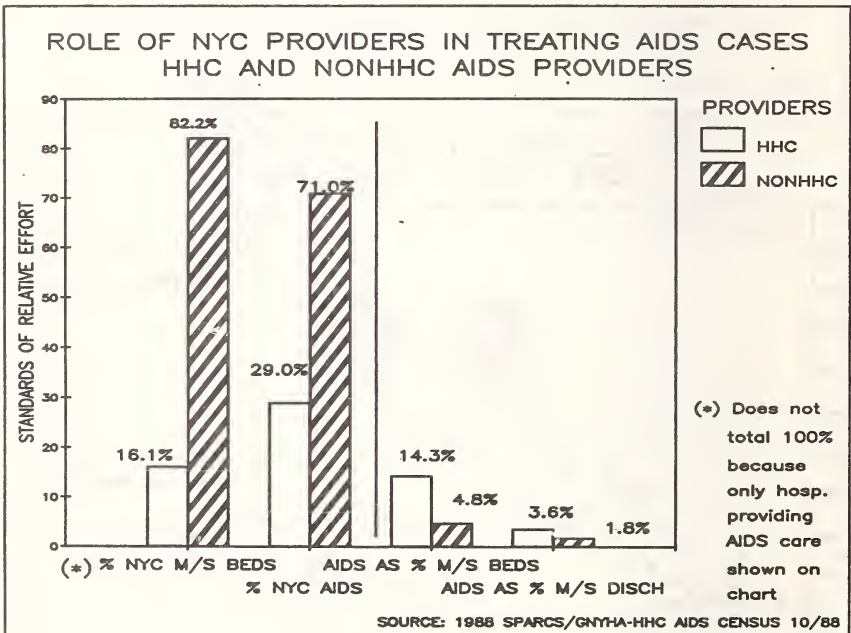
- HHC AIDS average daily census, as reported bi-weekly by clinical teams, increased from 199 in July 1985, when HHC began collecting data, to 550 in February 1989. This is an increase of 176.4%.
- When adjusted for undercounting (based on retrospective analysis of discharge data), the average daily census increased from 284 in April 1986 to 671 in February 1989.



## HHC HOSPITALS ARE AMONG THOSE THAT HAVE ASSUMED DISPROPORTIONATE RESPONSIBILITY FOR TREATING THE CITY'S AIDS PATIENTS

**HHC hospitals care for a disproportionate volume of AIDS cases compared to its med/surg bed capacity:**

- With 16.1% of med/surg beds (excluding ICU/CCU beds) among AIDS providers in the city, HHC served 29% of citywide AIDS discharges in 1988.
- AIDS patients filled an average of 14.3% of all HHC med/surg beds compared to only 4.8% among non-HHC hospitals during October 1988.
- The impact of AIDS on HHC's medical services is even greater (AIDS cases were 28.5% of HHC's medical bed complement in October 1988) because HHC has more medical beds in relation to surgical beds than non-HHC facilities.





## **HHC'S AIDS PATIENTS HAVE DIFFERENT PATTERNS OF HOSPITALIZATION**

**AIDS patients stay longer at HHC facilities.**

- ALOS averaged 24.9 days at HHC facilities and only 20.3 days at other NYC hospitals.

**Long staying AIDS cases are a far greater problem to HHC than non-HHC facilities.**

- Long stay cases comprised 21.5% of HHC's total adult AIDS caseload while they were 17.1% of the total adult AIDS caseload of all other NYC hospitals.
- Long stay days comprised 35.9% of total HHC AIDS days while they were only 23.6% of AIDS days at other facilities.
- Long stay days are increasing significantly; however, long stay days are growing more quickly at non-HHC facilities than at HHC facilities (increase of 113% vs. 104% from 1986-1988).

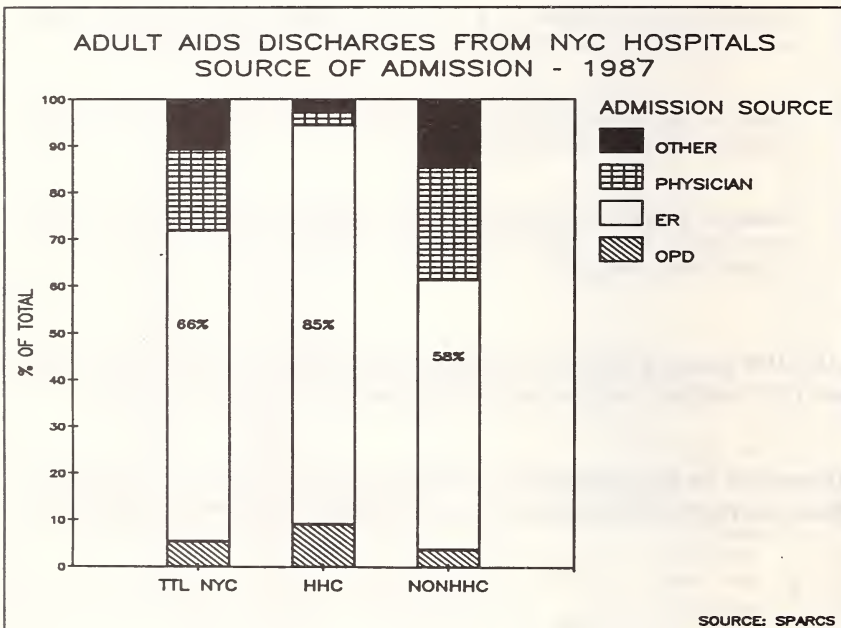
**If all AIDS patients could be discharged after 30 days, ALOS at HHC and non-HHC facilities would be nearly identical (15.9 days vs. 15.2 days).**

**Differences in hospitalization patterns can be largely attributed to differences in the AIDS populations treated by HHC and non-HHC hospitals.**

## HHC SERVES A DIFFERENT AIDS POPULATION

### Emergency Admissions:

- HHC treats 37.5% of all emergency AIDS admissions in NYC.
- Emergency admissions constitute 85% of all AIDS inpatients at HHC, compared to 58% among non-HHC facilities.
- For all AIDS admissions citywide, emergency AIDS admissions stay longer than those admitted on a nonemergent basis (22.8 vs. 19.3 days).

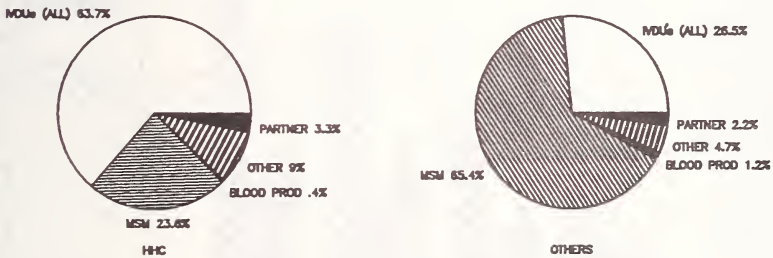


## HHC SERVES A DIFFERENT AIDS POPULATION (cont.)

### Transmission Groups:

- HHC exhibits a greater concentration of IVDUs with AIDS than other hospitals (63.7% vs. 26.5%).
- HHC hospitals treated over one half of all drug-related AIDS hospital discharges in 1988.

HHC AND OTHER NYC HOSPITALS - ADULT AIDS CASES  
DISTRIBUTION BY TRANSMISSION CATEGORIES



SOURCE: NYC DOH AIDS SURVEILLANCE UPDATE- Cases to date 7/88

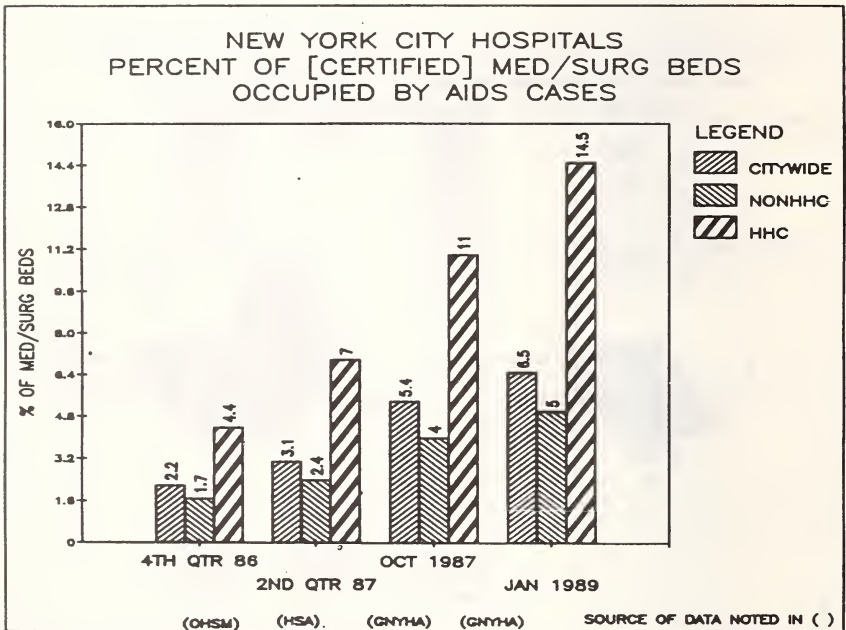


## IMPACT OF AIDS ON HHC

### THE AIDS EPIDEMIC HAS HAD A SERIOUS IMPACT ON HHC

The proportion of HHC's med/surg beds filled with AIDS patients has been consistently three times that of non-HHC hospitals.

- As noted earlier, the impact on HHC's medical services is greater (28% of medicine beds filled with AIDS patients) because HHC hospitals have proportionately more medical than surgical beds.

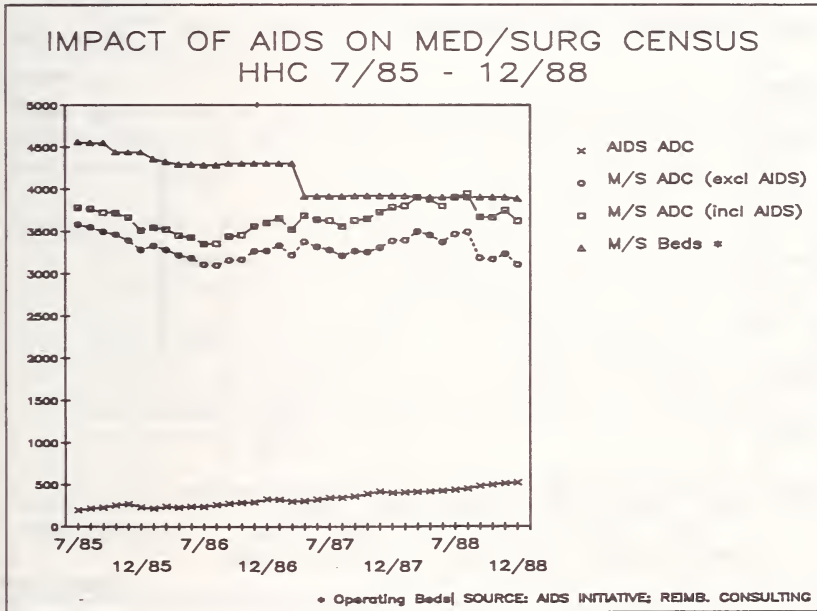


## AIDS HAS CONTRIBUTED TO OVERCROWDING AT HHC

At HHC hospitals, the census of AIDS patients has almost tripled since July 1985, from 199 to 550 in February 1989.\*

- AIDS is not the only factor contributing to med/surg overcrowding, however.
- HHC's med/surg beds decreased by 14 percent, or 630 beds, since 1985. Without this drop, occupancy would be 85.6 percent instead of 97.4 percent.
- The non-AIDS med/surg census has also risen 4 percent during the same period. With HHC's med/surg occupancies averaging 100%, the continued growth of AIDS patients raises concern about the access of other patients traditionally dependent on HHC. Citywide overcrowding suggests these patients may not be receiving the care they need.

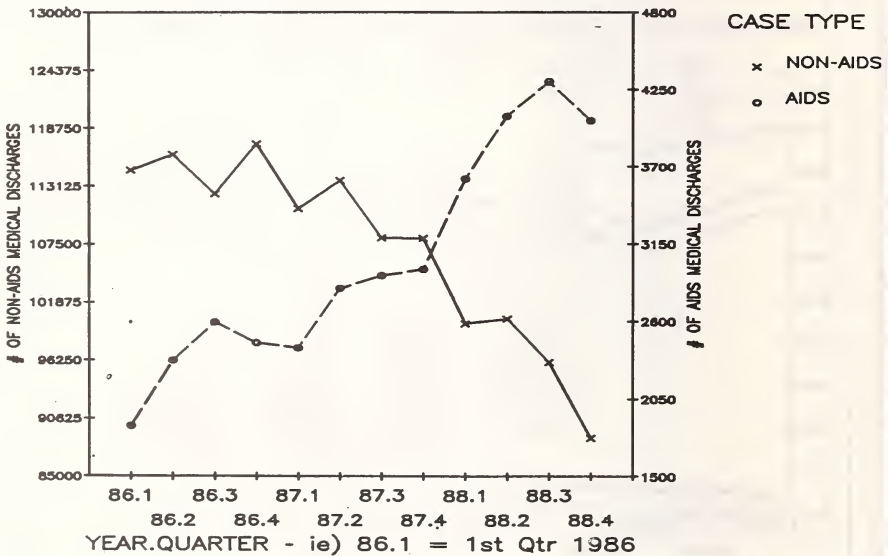
\* Based on weekly census counts; when adjusted per discharge database actual AIDS average daily census is about 35% higher.



## WITHOUT INCREASED BEDS, THE GROWTH OF AIDS AND OTHER CASES THREATENS ACCESS TO CARE IN NEW YORK CITY

- With nearly all med/surg beds in New York City at full capacity, the admission of AIDS and non-AIDS medical cases show an inverse relationship.
- Beginning in the second quarter of 1986, as AIDS cases rise, non-AIDS cases decrease, and vice versa. This trend continued through the 4th quarter of 1988.
- The same pattern is observed for patient days.

QUARTERLY TRENDS IN AIDS AND NON-AIDS MEDICAL DISCHARGES FROM NYC HOSPITALS - 1986-88



SOURCE: SPARCS

## SUMMARY AND CONCLUSIONS

### THE PRESSURES UPON HHC TO TREAT AIDS PATIENTS WILL INTENSIFY IN THE FUTURE

The AIDS epidemic has already placed intense pressure upon HHC to provide needed services, as is evident in the growing number of AIDS patients served by HHC and their growing proportion within HHC's caseload.

These pressures will intensify in the future as the epidemic shifts into populations traditionally served by HHC, including:

- » Low income and minority populations
- » Women and children
- » Populations residing outside of Manhattan, particularly those in the Bronx, Brooklyn, and Queens

These populations will not only need acute care services; they will need primary care, social services, housing and long term care -- services which are in even shorter supply.

Unabated, these pressures will result in:

- » Growing bed shortages and continued overcrowding in HHC's emergency rooms and med/surg units.
- » Displacement of patients traditionally served by HHC and compromises in access to care for all patients.
- » A growing dominance of AIDS patients within HHC's caseload, with serious consequences for physician and non-physician recruitment, HHC's teaching programs and ultimately the quality of care.

Alone, HHC cannot meet the growing need resulting from New York City's AIDS epidemic.



From the New England Journal of Medicine Editorials  
Vol. 320, No. 24, Pp. 1623-1624, June 15, 1989

# FEDERAL SPENDING ON AIDS — HOW MUCH IS ENOUGH?

IN this issue of the *Journal*, Winkenwerder and his colleagues report on federal spending to date for research, education, and medical care to cope with the crisis caused by the human immunodeficiency virus (HIV). They also project probable federal spending levels through 1992.<sup>1</sup> This is a careful, well-balanced piece, presenting solid evidence that will be gobbled up avidly and used vigorously to support the views of those who come down on either side of the question of the adequacy of our efforts to combat the epidemic of acquired immunodeficiency syndrome (AIDS).

Those who think that the federal response has been generous can marshal impressive evidence from this report to support their case. In the seven years from 1982 through 1988, federal spending for AIDS was \$5.4 billion. In 1989, more than \$2.1 billion will be spent — about 35 percent of the total expenditure for AIDS in the United States during the entire period and almost three times the total state expenditures. This figure compares favorably with the fraction of the total overall national health expenditures contributed by the federal sector (about 30 percent).

In 1989, expenditures on the HIV epidemic will consume 9.6 percent of the budget of the Public Health Service. This will rise to 13 percent in 1992. But within certain sectors of the Public Health Service, HIV-related spending in 1989 will consume the lion's share of their total funds. For example, it will consume 40 percent of the budget of the Centers for Disease Control, nearly 50 percent of the budget of the National Institute on Drug Abuse, and about 50 percent of the Food and Drug Administration budget. Furthermore, when federal spending for research, education, and the prevention of AIDS is compared with similar spending for other major diseases, it comes out looking quite respectable. Some of these data are shown in Table 1. Winkenwerder and his colleagues point out that if spending on the HIV epidemic continued to increase at such rapid rates, its fairness could be questioned with respect to levels of spending on other killer diseases. Also, the additional dollars might not result in a more rapid cure, and large bureaucracies often find it difficult to spend rapid infusions of money effectively.

But the authors also present potent data to support the view that we are spending too little on AIDS. I share this view; I believe that we are spending vastly too little on AIDS from the federal purse and are targeting some of it very poorly. Although the amount of

scientific knowledge about HIV infection that has been generated in a very short time has been breathtaking and bodes well for the future, the degree of human misery and suffering associated with AIDS far exceeds anything I have witnessed during my 40-year professional lifetime. What has happened to too many persons with AIDS is so heart-wrenching as to be almost unbelievable. It shames us as a nation. Not all this sorrow could have been prevented by increased expenditures on the disease, but some of the tragedies accompanying the AIDS epidemic could have been softened by better funding, coupled with aggressive but compassionate leadership at all levels.

For example, although we know precisely how HIV infection is transmitted and what behavioral changes must occur to cause a marked decrease in transmission, during the seven years from 1982 through 1988 we spent only \$1.1 billion on preventive education and almost nothing on research that would teach us what actually causes people to alter their behavior.<sup>1</sup> Compare this with the annual \$2 billion advertising budget of the tobacco industry<sup>2</sup> or the \$1.3 billion spent similarly each year by the liquor industry.<sup>3</sup> Or consider that although more than 89,000 Americans now have clinical AIDS, only 6200 are enrolled in federally funded therapeutic trials.<sup>4</sup> The disease is now shifting relentlessly to the intravenous drug-using community, but funds and facilities for the treatment of intravenous drug users are in scandalously short supply. New York City has an estimated 200,000 intravenous drug users with an HIV-positive seroprevalence rate of 40 to 70 percent, but it has facilities for treating fewer than 38,000 of them.<sup>4</sup> I know of no fatal disease that we treat in as cavalier a fashion as intravenous drug use. To curb the AIDS epidemic we must treat intravenous drug users effectively. We are failing miserably.

The source of the federal money spent for the clinical care of patients with AIDS is also a depressing proxy indicator of what happens financially to those with this malady. Almost 40 percent of patients with AIDS have their care paid for by Medicaid. This means that they must no longer have any financial resources of any size. AIDS is a virulent one-way ticket to poverty. Only about 1 percent of patients with AIDS receive assistance from Medicare, because very few of them survive the 24-month waiting period to qualify for benefits. Finally, although Winkenwerder and colleagues project that federal spending for AIDS

Table 1. Estimates of Federal Spending and Number of Deaths in 1989 with Respect to Selected Diseases.\*

DISEASE	SPENDING billions of dollars	DEATHS
Cancer	1.45	494,422
Heart disease	1.01	777,626
AIDS and HIV	1.31	34,368

\*Data are from Tables 4 and 5 of the paper by Winkenwerder et al.<sup>1</sup>

will rise to \$4.2 billion in 1992, this represents only 1.8 percent of the \$238 billion in total federal health spending projected for that year — an amount that pales in comparison with the estimated \$200 billion needed to bail out the thrift industry<sup>5</sup> or the \$128 billion estimated as necessary to clean up nuclear arms plants.<sup>6</sup>

A colleague and I have pointed out<sup>4</sup> that although our behavior during epidemics has always been the result of many forces — scientific, social, political, and economic — two aspects of the present epidemic have tended to make the national response to AIDS less generous or compassionate than that to which an enlightened society might aspire. First, this disease emerged initially in homosexual men and intravenous drug users — two groups that evoke strong negative or hostile feelings in many members of the larger society. AIDS has led not only to loss of life, but often to loss of job, family, housing, insurance, and any acceptable human support system along the way. It is a human tragedy made unspeakably harder by the way we have treated those who are afflicted.

Second, the highly focal nature of the epidemic geographically has tended to encourage national inaction. The massive spread of the virus and the knowledge that perhaps 1.5 million Americans are already infected and generally believed to be destined to die of AIDS should clearly have merited a massive federal response. But the fact that only five cities in five states — New York, New Jersey, California, Florida, and Texas — have more than two thirds of the cases has tended to blunt political interest elsewhere. Indeed, another five states — Vermont, Idaho, Montana, and the Dakotas — have each had fewer than 10 cases of AIDS in eight years.<sup>4</sup> Thus, their legislators have been understandably reluctant to give up funds that would benefit their constituents in order to help out urban megacenters.

Where are more federal funds needed? The white paper prepared for then President-elect Bush by Rob-in Weiss and the presidents of the National Academy of Sciences and of the Institute of Medicine answers this question clearly and succinctly.<sup>7</sup> I will simply emphasize my own priorities here.

First, we should provide adequate funding for intense, targeted education that is imaginatively directed at high-risk groups, particularly teenagers. A recent anonymous seroprevalence study of homeless 13-to-18-year-olds in New York City showed rates of HIV positivity of 6.88 percent in the male subjects and 5.56 percent in the female subjects.<sup>8</sup> This is terrifying, and it strongly suggests that heterosexual transmission of the virus is spreading rapidly.

At the same time, we should provide federal funds for disaster relief to help the cities most seriously affected by AIDS. New York City's overburdened health system is close to collapse. New funds are vitally needed to develop the facilities for short-term and long-term care, supportive residential units, and the

housing now in desperately short supply. Funds are also urgently called for to train the new personnel required to handle patients who are currently symptomatic and to prepare for the onslaught of those who will become so.

Finally, funds for basic research on the virus, its interaction with the human organism, and potential therapeutic agents and vaccines must be expanded as rapidly as our scientific talents permit. It would be shortsighted to take such funds away from ongoing basic research that is productive. New insights are coming from many sources.

But what is perhaps needed most in addressing the AIDS crisis is national leadership that will set a tone of appropriate concern coupled with swift, decisive action. The white paper sent to President-elect Bush closed with these words:

A further resource in the nation's efforts against AIDS is solely the [province] of the President — a resolve that the devastation caused by HIV infection will be prevented and its sufferers [will be] provided compassionate care, and an attitude that bespeaks that it solve.<sup>7</sup>

The proper mix of money, science, medical care, and human support for those who are infected with HIV is hard to achieve, but more federal funding — properly targeted, and accompanied by that leadership and resolve — could put us on a better, more effective and kindlier track.

Cornell University  
Medical College  
New York, NY 10021

DAVID E. ROGERS, M.D.

#### REFERENCES

1. Winkenwerder W, Kessler AR, Stolec RM. Federal spending for illness caused by the human immunodeficiency virus. *N Engl J Med* 1989; 320:1598-603.
2. Davis RM. Current trends in cigarette advertising and marketing. *N Engl J Med* 1987; 316:725-32.
3. Impact 1988; 18(3):1-12.
4. Roit A, Rogers DE. AIDS in the United States: patient care and politics. *Daedalus* 1989; 118(2):41-58.
5. Rudolph B. Finally the bill has come due. *Time*. February 20, 1989; 133(8):68-73.
6. Peterson C. Energy department says cleanup could cost \$128 billion. *Washington Post*. January 5, 1989:A3.
7. Weiss R. A national strategy on AIDS. *Issues Sci Tech* 1989; 4(3):52-9.
8. New York State Department of Health. AIDS in New York State through 1988. Albany, N.Y.: New York State Department of Health, 1989:15.



United States  
General Accounting Office  
Washington, D.C. 20548

---

Human Resources Division

B-236204

September 13, 1989

The Honorable Edward M. Kennedy  
Chairman, Committee on Labor  
and Human Resources  
United States Senate

The Honorable Henry A. Waxman  
Chairman, Subcommittee on Health  
and the Environment  
Committee on Energy and Commerce  
House of Representatives

This report examines the availability of health and social services for people with acquired immunodeficiency syndrome (AIDS) in five communities. Although AIDS is spreading across the country, little is known about how communities other than New York City and San Francisco are delivering and financing care for people with AIDS. Therefore, we visited state and local officials and other health experts in New Haven, Baltimore, Philadelphia, New Orleans, and Seattle to begin to ascertain how they are dealing with the AIDS epidemic.

We are sending copies of this report to the Secretary of Health and Human Services and other interested parties. Major contributors to the report are listed in appendix II.

A handwritten signature in cursive script that reads "Janet L. Shikles".

Janet L. Shikles  
Director, Health Financing  
and Policy Issues

---

## Executive Summary

---

### Purpose

Acquired immunodeficiency syndrome (AIDS) is a relatively new and incurable infectious disease with profound implications for health care delivery, financing, and public policy. Since AIDS was first identified in 1981, nearly 100,000 people have been diagnosed with the disease and more than 55,000 have died. By the end of 1992, the Public Health Service predicts that 365,000 people will have been diagnosed with AIDS and 263,000 of them will have died. Medical care costs related to AIDS are projected in the range of \$5 to \$13 billion in 1992.

Not only is the AIDS epidemic continuing to spread, but the patient population is expanding to include more intravenous (IV) drug users, minorities, women, and children. And, as medical science progresses, people with AIDS are living longer and requiring more chronic care services.

At the same time, AIDS is spreading geographically to hundreds of smaller American cities. Little is known, however, about how communities outside New York City and San Francisco finance and deliver care to people with AIDS. To help fill this information void, GAO examined AIDS health services in five communities—New Haven (Connecticut), Philadelphia, Baltimore, New Orleans, and Seattle. The review focused on:

- how the communities delivered and financed health services for people with AIDS, and
- the federal implications of community and state actions.

---

### Background

AIDS is the final stage of a disease process caused by the human immunodeficiency virus (HIV). As a result of damage to the immune system caused by HIV, people with AIDS are vulnerable to a wide range of life-threatening infections and cancers. The health care needs of AIDS patients vary widely depending on multiple medical problems and the stage of illness. For example, AIDS patients may need acute care in a hospital, regular treatment through outpatient clinics, or chronic care in an institution or at home during the course of the disease.

The federal government has invested most of its AIDS funding in biomedical research, education, and prevention activities. Viewed largely as a state and local responsibility, service delivery has received much less federal support. Instead, most federal dollars for patient care have been spent on Medicaid recipients with AIDS.



---

## Results in Brief

The federal government, through the Medicaid program, pays at least 25 percent of the nation's AIDS medical care bill. In communities like San Francisco, high-quality care is available at lower cost than in other cities because alternatives, such as home and community-based services, substitute for hospital-based care. As the epidemic progresses across the country, Medicaid as well as private insurers will pay for more expensive AIDS health services if communities have not developed lower-cost alternative delivery systems. Therefore, the federal government has a strong financial incentive to encourage less costly, quality-conscious AIDS delivery systems.

GAO's review indicates that communities will experience different problems in providing AIDS services. Over the next several years, many communities will need help developing and coordinating health services to meet the needs of their growing AIDS caseloads. Modest federal and private demonstration projects, such as those now underway in some cities, allow communities broad flexibility to develop alternative services tailored to their unique needs. Expanded assistance to more communities and wide dissemination of results from AIDS-related demonstration projects have the potential to help many communities replicate successful AIDS delivery systems or create their own. Such assistance and sharing of information can help to control the costs of caring for people with AIDS.

---

## GAO's Analysis

GAO reviewed AIDS population characteristics, service availability, and payment for services in five communities. Demand for certain AIDS services in some communities already has exceeded capacity, and other services were not available at all.

---

### Growing AIDS Populations Differ

The size of the AIDS populations of the five communities had doubled nearly every year since 1981. Nationwide AIDS statistics tended to mask the uniqueness of AIDS populations in individual communities, which ranged from those made up almost exclusively of homosexuals to those predominantly made up of or related to iv drug users. Racial characteristics of the AIDS populations also varied considerably among the communities. Most cities, even those with primarily homosexual AIDS populations, expected growth in their iv drug cases. (See ch. 2.)

## Service Gaps Remain

The availability and adequacy of health services for people with AIDS varied according to the nature of the communities' AIDS populations and their health resources. (See ch. 3.)

- Hospital care was generally available for people with AIDS. Increasing AIDS caseloads were straining inpatient capacity, however, in part because only a few hospitals in each community were treating AIDS patients. (See pp. 28 to 29.)
- Outpatient medical care provided by physicians and clinics was reaching capacity, and some clinics had waiting lists. (See pp. 30 to 33.)
- In most of the communities, nursing homes did not admit people with AIDS because of limited capacity, lack of facilities and staff to care for infectious patients, and low Medicaid reimbursements. (See pp. 33 to 37.)
- Many home and community-based services were not available to AIDS patients who needed them because both capacity and insurance coverage were limited. These services included home nursing and attendant care, case management, mental health services, substance abuse treatment, and dental care. (See pp. 36 to 42 and 32 to 33.)
- The lack of housing for AIDS patients was a serious problem in all five communities. (See pp. 42 to 43.)

## Medicaid Is Leading Payer

Although data on AIDS care costs and financing were poor, it appeared that Medicaid paid for 30 to 50 percent of AIDS hospitalizations in the five communities. In some communities, Medicaid's share may be increasing. As the epidemic grows and affects increasing numbers of IV drug users, minorities, women, and children, state and federal governments can expect increasing Medicaid expenditures for AIDS care. (See ch. 4.)

State Medicaid programs are complex systems for AIDS patients to negotiate, as they are for other recipients. Government and health officials in the five communities reported problems with eligibility, limited service coverage, and low reimbursement rates that in some cases prevented Medicaid programs from serving AIDS patients as effectively as possible. These problems were not unique to AIDS patients, but sometimes were accentuated for them. (See pp. 48 to 54.)

## Recommendations

This report contains no recommendations.

## Agency Comments

GAO did not request official agency comments on a draft of this report. However, key officials and providers from the communities that GAO studied reviewed draft summaries of findings for their sites, and their views have been incorporated in the report where appropriate.

A Comparative Analysis of AIDS Service  
Demonstration Projects in  
Los Angeles, Miami, New York, and San Francisco

FINAL REPORT

October 16, 1989

Submitted to the  
Health Resources and Services Administration

by

Roxanne Andrews  
Project Manager

Bonnie Preston  
Project Analyst

Embry Howell  
Project Director

Margaret Keyes  
Project Analyst

Contract Number 240-88-0010

SysteMetrics/McGraw-Hill, Inc.

Research Assistance throughout the project was provided by: Sarah Baily, Christopher Clune, Michael Haag and Vanessa Nora. Clerical Support was provided by: Denise Johnson, Ann Miles, Ann Prindle, and Patricia Summers.

## I. INTRODUCTION

### A. PURPOSE OF THE STUDY

In October 1986 the Health Resources and Services Administration (HRSA) awarded three-year grants in Los Angeles, Miami, New York and San Francisco to initiate AIDS Service Demonstration projects. The overall goals of these projects were to:

1. Identify unmet needs and develop ways to meet those needs.
2. Provide for integration of community resources through effective coordination.
3. Ensure continuity of services through effective case management.
4. Reduce overall costs of providing medical care to AIDS patients by providing alternatives to inpatient hospital care.

The major purpose of this study was to describe the context in which each of the demonstration projects evolved, the factors which affected the development of AIDS services in the communities, the state of program development at the time of the study and the role that the HRSA grant played in this development. A separate case study report was written on each of the four communities. HRSA hopes that a description of AIDS service development in the cities that have experienced the earliest and greatest impact of AIDS will help other localities plan for AIDS services.

This report presents an analysis of the major issues emerging from the case studies of the four sites including: role of the HRSA grant in service development, factors affecting overall system development, service development for specific populations, case management, and the development of coordinated systems of care for people with AIDS.



## Exhibit III-1

Characteristics of Phases in the  
Evolution of AIDS Service Delivery SystemsPhase 1: Initial Response

Community-based organizations are started by members of the gay community

- Initial hotline, support services and education

Hospital(s), primarily public, begin treating a number of AIDS patients  
Education begins

Phase 2: Building the System's Foundation

Hospitals establish inpatient programs and training  
Outpatient clinic for AIDS open  
State/local funding is targeted for AIDS  
State/local AIDS offices are established

Phase 3: Broadening the Response

Case management services begin  
AIDS home health care programs begin  
AIDS housing is initiated  
Dedicated AIDS inpatient units are established  
Major community-based organizations increase use of professional staff  
Community-based organizations target minority community  
Planning activities to develop coordinated approach begin

Phase 4: AIDS Services Begin to Become Institutionalized

AIDS services are established in community clinics  
Data systems created for case management and tracking service use  
Housing initiatives and alternative levels of care expanded  
Services for IVDA population are targeted  
Services for minority populations continue to be targeted

Phase 5: AIDS Services are Institutionalized (Future Development)

Emphasis on early intervention  
Emphasis on treatment as a chronic disease  
Mainstreaming of AIDS services  
System of financing services for AIDS becomes established  
Effective service systems for IVDAs and minorities are developed

## V. CONCLUSIONS

The four communities studied have made significant advancements in the development in AIDS services with the assistance of HRSA funds. In addition to increasing the overall level of funding for AIDS services, the HRSA demonstration program, unlike most other funding sources, allowed communities the flexibility to target funding to aspects of the system in greatest need of further development. The following service needs remain most severe in these communities:

- Basic services for the gay/bisexual HIV-infected population need additional support because of the continued increase in caseloads and because traditional sources of reimbursement do not cover many of these services.
- Services for the minority and IV drug user populations are the most underdeveloped and these populations are not being adequately reached or served.
- Housing services of various types and drug treatment are in serious short supply.

The HRSA demonstration projects have made initial advancements in these areas through the development of numerous model programs. Replicating and expanding these programs, as well as developing new approaches to the most critical service needs, should be the priority of funders of AIDS service development such as HRSA.

## VI. RECOMMENDATIONS

The following are recommendations for HRSA to consider in future funding of HIV service development:

1. Do these communities continue to need funding from programs like the HRSA AIDS Service Demonstration program?

Continued and increased funding is needed to keep pace with the rising AIDS caseload and to address the development of specific services needed in each community. There is no indication that other sources of funding will be forthcoming in sufficient amounts to meet these needs.

Recommendation:

- HRSA should continue funding the AIDS Service Demonstration programs in these communities and target funding to areas in most need of development and for which other sources of funding are not likely to be forthcoming.

2. What services should be targeted for development?

Basic health and social services to the gay/bisexual population need to increase because of increasing caseload. Services for IV drug users and minorities are the most underdeveloped relative to need. Housing services of various types are also in short supply.

Recommendation:

- HRSA should continue its support of basic services for all risk groups.
  - Additional funding for the development of model programs for IV drug users and minorities should be provided.
  - Special funding should be provided to assist communities to develop housing services for people with AIDS and increase drug treatment programs.
3. Should the goals of the demonstration program be more specifically stated?

The four service demonstration goals do not incorporate some of the operating assumptions that HRSA made has concerning the best approach to building an AIDS service system.

Recommendation:

- HRSA should examine its assumptions concerning AIDS service development and incorporate them into the goals.
- HRSA should incorporate phase-specific goals for communities in different stages of development.
- Planning activities should be encouraged in the early phases of service development.

4. What are the necessary grantee characteristics to successfully administer the grant?

The type of organization administering the grant influences the achievement of the HRSA goals through its ability to translate goals into local policy and through its interest and/or ability to foster coordination of activities.

Recommendation:

- HRSA should fund organizations with demonstrated ability to influence local politics and the ability to foster coordination of activities.
- Require local government grantees to have a coordinating body of providers and community groups to provide for their involvement in designing, developing, and operating HIV services.
- For non-government grantees, demonstrated leadership ability and safeguards against self-interest should be required.

5. What geographic scope should the demonstration projects have?

The geographic scope of the demonstration projects does not always correspond to the existing boundaries of the local health services system.

Recommendation:

- HRSA should assure that the geographic scope of service demonstration projects matches local health service system boundaries (generally defined by local government jurisdiction boundaries).
- In large communities with subsystems, subcontracts to local consortia should be encouraged.

6. How can HRSA help other communities gain from the experience of these four communities?

The demonstration projects have developed many programs that can be used as models by other communities that are developing AIDS service systems. Successful projects are burdened by providing technical assistance to other communities.



Recommendation:

- HRSA should foster dissemination of information about the demonstration projects. This should include wide distribution of evaluation reports on the service demonstration projects.
- The demonstration grants should explicitly support some activities related to information exchange with other communities.

## Medicaid Reimbursement Rates Are Very Low For Common AIDS Related Physician Services

<u>Service</u>	<u>Medicaid</u>	<u>Medicare</u>	<u>Blue Cross</u>
Office Visit	\$ 7.00	\$ 80.40	\$ 78.00
Hospital Visit	\$ 6.50	\$ 78.40	\$102.00
Bone Marrow Biopsy	\$12.00	\$165.10	\$240.00
Endoscopy	\$20.00	\$ 78.40	\$ 80.00
Bronchoscopy	\$60.00	\$638.20	\$675.00

Medicaid and Blue Cross Rates are for NY State

# The 1987 US Hospital AIDS Survey

Dennis P. Andrusis, MPH, PhD; Virginia Beers Weslowski, MPA; Larry S. Gage, JD

In 1987, the National Public Health and Hospital Institute conducted a national survey of 623 acute-care hospitals to obtain information relating to inpatient and outpatient care for persons with acquired immunodeficiency syndrome (AIDS). Two hundred seventy-six hospitals reported treating persons with AIDS; the average length of stay was 16.8 days. Average costs and revenues per inpatient day were \$681 and \$545, respectively, with a cost per patient per year of \$17 910. Estimated cost for AIDS inpatient care during 1987 was \$486 million; Medicaid represented the primary payer. Regional and ownership comparisons for this year and between 1985 and 1987 indicated significant differences in utilization, payer source, and financing. Results suggest major differences in reimbursement and losses related to payer source or lack of insurance, with many hospitals that serve large numbers of low-income persons with AIDS encountering moderate to severe financial shortfalls. We conclude that increasing concentrations of persons with AIDS in relatively few hospitals in large cities may make it more difficult to secure the broader political base necessary to obtain adequate support for treatment.

(JAMA. 1989;262:784-794)

THE DECADE of the 1980s has seen a major increase in the number of people with acquired immunodeficiency syndrome (AIDS) in the United States. According to the Centers for Disease Control (CDC), 99 936 individuals have been diagnosed with AIDS as of June 30, 1989.<sup>1</sup> Projections for the future indicate a continuing escalation in the number of people suffering from AIDS and other human immunodeficiency virus (HIV)-related conditions.

While some states and localities have been successful in developing community programs to respond to the rapidly growing need for health services, hospital-based treatment remains the primary and, frequently, the only source of

care for people with AIDS (PWAs). Several studies have attempted to monitor the costs of care in the hospital.<sup>2-4</sup> Other research has used statistics on hospital-based care and other sources of information to project patient-specific and national direct, indirect, or lifetime costs.<sup>5-9</sup> However, few studies have examined hospital care for AIDS patients from a national perspective.<sup>10,11</sup>

This report presents national information on patient characteristics and hospital treatment and financing of care to PWAs during 1987. It also compares the 1987 information reported by teaching hospitals with teaching hospital data from our 1985 hospital AIDS survey.

## METHODS

In March 1988, the National Public Health and Hospital Institute disseminated a survey to 623 members of four hospital associations: the National Association of Public Hospitals and the Association of American Medical Colleges'

Council of Teaching Hospitals, which together represent 465 metropolitan area public and private teaching institutions; the National Association of Children's Hospitals and Related Institutions, which represents 90 facilities and pediatric departments within general acute-care hospitals; and the 91 members of the National Council of Community Hospitals, which represents primarily nonprofit hospitals and hospital systems (overlap in membership accounts for the total of 623 institutions). The survey requested hospitals to provide information from the 1987 calendar year on patients diagnosed with AIDS. (The survey requested information on patients who met the CDC definition for AIDS. Hospitals were asked, if possible, to use the extant definition for the first 8 months of 1987 and the definition as revised on September 1, 1987, for the last 4 months.) The results reported herein do not include other HIV-related illnesses, which represent a large, if difficult to measure, portion of AIDS care.

Institutions were asked to respond to questions in six specific categories: general inpatient utilization; demographic and risk-group characteristics; hospital organization and staffing of AIDS treatment programs; outpatient information; financial characteristics of inpatient and outpatient care; and specific treatments available for AIDS patients. Hospitals were also asked to report cost, charge, and revenue per day for their other (non-AIDS) medical/surgical patients. All information was reported in the aggregate for each hospital. Institutions that failed to respond to our March mailing received a second mailing in June 1988. As necessary, hospitals were telephoned to clarify reported information. Excluded from the analysis were 72 Veterans Administration hospitals and

From the National Public Health and Hospital Institute (Dr Andrusis and Ms Beers Weslowski) and the National Association of Public Hospitals (Mr Gage), Washington, DC.

Reprint requests to National Public Health and Hospital Institute, 1001 Pennsylvania Ave NW, Suite 635, Washington, DC 20004 (Dr Andrusis).

Table 1.—1987 Hospital Utilization Characteristics for AIDS Patients

	Total	Average per Hospital	Median
No. of responding hospitals with AIDS patients	276	...	...
Public	90 (29%)	...	...
Private	196 (71%)	...	...
No. of patients	14,145	51	13
Public	7030 (50%)	88	32
Private	7115 (50%)	36	9
No. of admissions	22,088	80	20
Public	10,812	133	49
Private	11,476	59	15
No. of admissions per patient per year	...	1.6	...
Public	...	1.5	...
Private	...	1.6	...
No. of inpatient days	371,768	1347	313
Public	187,656	2346	829
Private	184,112	939	234
Average length of stay*	...	16.8	...
Public	...	17.7	...
Private	...	16.0	...
Average No. of days per patient per year	...	26.3	...
Public	...	26.7	...
Private	...	25.9	...
No. of outpatients	7602	89	10
Public	5326	161	36
Private	2276	44	3
No. of outpatient visits†	61,897	728	104
Public	48,171	1460	472
Private	13,726	264	42

\* Average length of stay (ALOS) is derived by dividing inpatient days by admission.

† As reported by 85 hospitals: 33 public and 52 private.

3 non-US hospitals, which reduced the universe of hospitals to 548.

Statistical analysis consisted of comparisons of group means via *t* tests and paired sample *t* tests and comparisons of proportions via  $\chi^2$  tests.

#### Response Group Representativeness

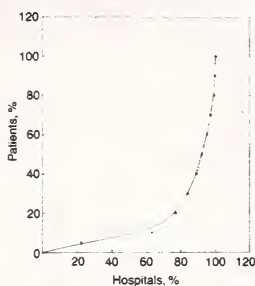
Several analyses were undertaken to determine the generalizability of the information reported. We compared the group of hospitals responding to the survey with the nonresponding members of the four associations on the basis of number of beds, ownership, and region. The response group and nonresponse group contained similar proportions of hospitals from the Northeast and West, with the Northeast comprising 30% of the response group and 32% of the non-response group. The West represented 16% and 15%, respectively. The Midwest was slightly overrepresented in the response group (28% of the response group vs 23% of the nonresponding hospitals), while hospitals in the South were somewhat underrepresented (26% of the response group vs 31% of the nonresponding hospitals). By owner-

ship, public hospitals (defined as city-, county-, or state-owned or operated institutions) were slightly overrepresented in the response group (28% of the response group, compared with 24% of the nonresponding facilities). There were no differences in the average number of beds per hospital between responding and nonresponding hospitals.

To determine if the information from our survey was generalizable to the universe of PWAs, we compared patients on the basis of demographic and risk group characteristics for the responding hospitals with those reported to the CDC. The results of this comparison, reported herein, indicated some differences in the composition of the patient populations.

#### RESULTS

Three hundred twenty-two hospitals located in 39 states responded to the survey, representing 59% of the non-Veterans Administration, US members of the four associations. Of these respondents, 46 indicated that they treated no AIDS patients during calendar-year 1987. The 276 hospitals that reported treating at least one AIDS pa-



Distribution of inpatients in hospital. Percent of patients plotted against percent of hospitals for 14,145 patients and 276 hospitals.

tient for that year constitute the response group on which this analysis is based.

The 14,145 patients treated in these hospitals accounted for 371,768 inpatient days and 22,088 admissions, and represented 52% of the 276 PWAs estimated by the CDC to be alive at any time during 1987 (Meade Morgan, CDC, personal communication, December 19, 1988) (Table 1). These institutions treated an average of 51 AIDS inpatients in that year (range, 1 to 799 patients) and reported 1.6 admissions per inpatient per year. The average patient received 26 days of inpatient care, with a length of stay of 16.8 days per admission.

Eighty-five hospitals identified 7602 AIDS outpatients treated during this period, an average of 89 per institution. They accounted for 61,897 visits, which equaled 8.1 visits per person per year and 728 visits per facility per year. (Although hospitals were asked to provide outpatient information on AIDS and AIDS-related complex separately, several were unable to do so; therefore, an unknown number of patients with AIDS-related complex were likely to be included in the outpatient data.)

The distribution of AIDS patients in hospitals points out an important aspect of the patterns of treatment of PWAs (Figure). The graph shows that a very small number of hospitals are treating very large numbers of PWAs. Ten percent (28) of the hospitals treated 58% of the patients, with 10 hospitals (4%) treating 32% of the patients. Of these 10



Table 2.—Hospital Characteristics by Ownership and Location\*

	Overall Total	Northeast			Midwest			South			West		
		Total	Public	Private	Total	Public	Private	Total	Public	Private	Total	Public	Private
No. of hospitals responding	276	84	18	66	77	16	61	71	21	50	44	26	18
% of total by region			30		28			26			16		
No. of patients													
Total	14145	6677	2951	3926	1459	469	990	3452	1900	1552	2357	1710	647
Average per hospital	51	82	164	59	19	29	16	49	90	31	54	66	36
Median	13	25	143	13	9	21	7	12	32	10	18	21	8
% of total by region			49		10			24			17		
% of CDC-reported cases by region (cumulative through December 28, 1987)			39		8			26			27		
No. of admissions													
Total	22088	10380	4238	6142	2410	702	1708	5479	2675	2804	3819	2997	622
Average per hospital	80	124	235	93	31	44	28	77	127	56	87	115	56
Median	20	43	222	22	15	46	10	19	37	14	22	28	11
No. of admissions per patient per year	1.6	1.5	1.4	1.6	1.7	1.5	1.7	1.6	1.4	1.8	1.6	1.8	1.3
No. of inpatient days													
Total	371768	216237	103730	112507	32011	9617	22394	75527	36871	38656	47993	37438	10555
Average per hospital	1347	2574	5763	1705	416	601	367	1064	1756	773	1091	1440	586
Median	313	589	531	362	213	521	155	322	612	203	293	326	244
Average length of stay	16.8	20.8	24.5	18.3	13.3	13.7	13.1	13.8	13.8	13.8	12.6	12.5	12.8
Average No. of days per patient per year	26.3	31.4	35.2	28.7	21.9	20.5	22.6	21.9	19.4	24.9	20.4	21.9	16.3

\*CDC indicates Centers for Disease Control.

Table 3.—Risk-Group Characteristics by Ownership and Location\*

	% of CDC-Reported Cases (Cumulative Through December 28, 1987)	Overall			Northeast			Midwest			South			West		
		Total	Public	Private	Total	Public	Private	Total	Public	Private	Total	Public	Private	Total	Public	Private
No. of patients		10384	5408	4976	5464	2539	2925	1007	359	648	2609	1496	1113	1304	1014	280
No. of hospitals responding		235	67	168	75	17	58	67	14	53	60	20	40	33	18	17
Risk group, %																
Homosexual	66	54	44	66	40	18	60	75	73	76	64	57	74	78	77	79
Homosexual IV drug user	8	8	8	4	5	6	3	7	10	5	7	10	4	8	10	4
Heterosexual IV drug user	17	27	36	17	43	66	24	7	9	7	11	12	9	4	8	1
Sexual partner of risk-group member	4	3	3	3	4	4	4	3	2	3	2	2	2	3	3	2
Child of risk-group member	1	6	8	5	5	5	5	1	1	1	11	14	6	1	0	2
Blood-product related	4	4	3	5	3	1	4	7	5	8	5	5	5	6	4	12

\*CDC indicates Centers for Disease Control; and IV, intravenous.

hospitals, 6 are public and 4 are private. The concentration of patients and services in a few hospitals is reflected in the utilization variables summarized in Table 1.

#### AIDS Hospital Utilization Characteristics

Caseloads varied across regions. Institutions in the Northeast reported treating the greatest number, 82 patients per facility. Public hospitals treated, on average, more than twice as many AIDS patients as private hospitals in 1987 (88 and 36, respectively) ( $P < .001$ ) (Table 1). Public hospitals in

the Northeast treated the greatest number per facility (164), followed by public institutions in the South (90) (Table 2).

There were no significant differences in average length of stay (ALOS) overall among regions or between public and private hospitals overall. However, the northeastern public hospitals' ALOS (24.5 days) was significantly longer than public hospitals in the Midwest (13.7 days) and public hospitals in the South (13.8 days) ( $P < .01$ ). Hospitals in the Northeast reported the highest number of days per patient per year, 31.4, and public hospitals in this region reported

the highest of all categories, 35.2 days per patient per year.

#### DEMOGRAPHIC AND RISK-GROUP CHARACTERISTICS AIDS Risk-Group Characteristics

Homosexual individuals with AIDS constituted the largest risk-group category of AIDS patients (54%), followed by heterosexual drug users (27%) (Table 3). Children of risk-group members constituted 6% of the PWAs reported.

The CDC reported a higher proportion of homosexuals (66%) and a lower proportion of drug users (17%) and children of risk-group members (1%) than

Table 4.—Demographic Characteristics by Ownership and Location\*

	% of CDC-Reported Cases (Cumulative Through December 28, 1987)	Overall			Northeast			Midwest			South			West		
		Total	Public	Private	Total	Public	Private	Total	Public	Private	Total	Public	Private	Total	Public	Private
No. of patients†	...	12856	7970	4886	5169	2999	2170	1322	555	767	4630	3098	1532	1735	1318	417
No. of hospitals responding	...	253	74	179	74	17	57	71	16	55	69	20	49	39	21	18
Race, %																
W	60	46	39	57	28	15	46	69	61	74	48	44	57	76	76	76
B	25	35	39	29	44	52	31	24	32	18	39	40	36	10	10	9
Hispanic	14	17	20	12	26	30	21	5	6	5	12	15	5	11	12	10
Other	1	2	2	2	2	3	2	2	1	3	1	1	2	3	2	5
Sex, % male	92	85	82	89	81	75	85	94	93	94	86	83	92	95	94	96
Age, y (%)																
0-4	1	4	4	3	4	4	4	1	1	1	5	6	3	1	0	2
5-12	1	1	1	1	1	0	1	0	1	2	3	1	1	1	1	3
13-19	0	3	5	1	1	1	1	0	1	9	12	2	1	0	1	1
20-29	21	22	24	20	20	21	19	28	32	26	22	23	19	23	28	13
30-39	46	44	44	44	47	50	44	45	46	45	40	37	46	44	44	44
40-49	21	19	16	22	20	18	22	17	15	18	16	14	21	21	20	25
50+	10	7	6	9	7	6	9	7	6	8	6	5	8	9	7	12

\*CDC indicates Centers for Disease Control.

†Due to differences in item responses rate, the number of patients represented in each category is not identical. Based on admissions rather than patients for an unknown number of hospitals. Therefore, the number of patients in some columns may be greater than the figures reported in Tables 1 and 2.

Table 5.—Percent Inpatient Admissions: Payer Source by Ownership and Location

	Overall			Northeast			Midwest			South			West		
	Total	Public	Private	Total	Public	Private	Total	Public	Private	Total	Public	Private	Total	Public	Private
No. of admissions	18,376	9917	8459	8593	3847	4746	2051	525	1526	4286	2634	1652	3446	2911	535
No. of hospitals responding	241	73	168	74	17	57	66	12	54	64	21	43	37	23	14
Payer source, %															
Medicaid	44	52	34	54	71	40	35	46	31	18	18	17	55	58	41
Private insurance	29	13	48	29	10	45	44	24	50	30	13	57	19	15	40
"Self pay"/"other"	23	31	13	11	13	10	17	21	16	48	65	22	23	24	15
Medicare	2	2	3	2	2	2	3	4	3	2	2	3	3	3	4
Prisoner	2	2	2	4	4	3	1	5	0	2	2	1	0	0	0

Table 6.—Percent of Outpatient Visits: Payer Source by Ownership and Location

	Overall			Northeast			Midwest			South			West		
	Total	Public	Private	Total	Public	Private	Total	Public	Private	Total	Public	Private	Total	Public	Private
No. of visits	40,802	33,658	7144	7645	2357	5288	2313	1385	928	12,638	12,435	203	18,206	17,481	725
No. of hospitals responding	70	28	42	18	3	15	16	6	12	20	12	8	14	7	7
Payer source, %															
Medicaid	31	26	56	58	56	59	46	47	44	19	18	67	27	25	52
Private insurance	15	14	18	14	8	16	23	24	20	11	11	17	16	16	22
"Self pay"/"other"	50	57	17	19	35	13	26	21	34	69	70	15	53	54	25
Medicare	3	3	2	2	1	2	4	6	2	1	1	1	4	5	1
Prisoner	1	0	7	7	0	10	1	2	0	0	0	0	0	0	0

responding hospitals. Similar proportions between the hospital study group and CDC estimates were found for the other risk-group categories. Overall,  $\chi^2$  tests confirmed that risk-group proportions differ for the two patient groups (survey and CDC,  $P < .001$ ).

Risk group was associated with both ownership and region ( $P < .001$ ). Hospitals in the Northeast treated signifi-

cantly fewer homosexuals (40%) and a significantly greater number of heterosexual drug users (43%) than hospitals in all other regions. Southern institutions treated proportionally more children (14%) than all other regions.

#### Demographic Characteristics

As expected, the great majority (85%) of AIDS patients fell within an

age range of 20 to 49 years (Table 4). Eighty-five percent were male. By race, 46% were white, 35% black, and 17% Hispanic.

Comparing the survey results with cases reported by the CDC (cumulative through 1987) indicated that the responding hospital group treated a greater number of women (15% vs 8% reported by the CDC), a greater

Table 7.—Average Inpatient Costs, Revenues, and Charges by Ownership and Location

	Overall			Northeast			Midwest			South		
	Total	Public	Private	Total	Public	Private	Total	Public	Private	Total	Public	Private
AIDS inpatients*												
No. of days	144 478	49 512	94 966	72 494	13 395	59 099	18 029	5 710	12 319	41 383	18 515	22 868
No. of hospitals responding	148	37	111	42	4	38	44	8	36	45	14	31
Cost per day, \$	661	709	666	658	758	636	745	764	737	658	618	691
Cost per admission, \$	11 441	12 549	10 656	13 686	18 571	11 639	9909	10 467	9655	9080	8528	9536
Cost per patient per year, \$	17 910	18 923	17 236	20 661	26 682	18 253	16 315	15 662	16 656	14 410	11 989	17 206
Charge per day, \$	864	879	855	789	861	773	1007	859	1075	852	755	930
Charge per admission, \$	14 515	15 558	13 680	16 411	21 095	14 146	13 393	11 766	14 083	11 758	10 419	12 834
Charge per patient per year, \$	22 723	23 461	22 127	24 775	30 307	22 185	22 053	17 610	24 295	18 659	14 647	23 157
Revenue per day, \$	545	491	574	536	651	510	614	538	650	483	232	587
Revenue per admission, \$	9156	8691	9184	11 149	15 950	9333	8166	7371	8515	6665	3202	9481
Revenue per patient per year, \$	14 334	13 105	14 855	16 830	22 915	14 637	13 447	11 029	14 690	10 578	4501	17 106
(Loss)-gain per admission, \$	(136)	(218)	(92)	(122)	(107)	(126)	(131)	(226)	(87)	(175)	(386)	(4)
(Loss)-gain per patient per year, \$	(2285)	(3859)	(1472)	(2536)	(2622)	(2306)	(1742)	(3096)	(1140)	(2415)	(5327)	(55)
(Loss)-gain per patient per year, \$	(3577)	(5818)	(2381)	(3831)	(3766)	(3616)	(2869)	(4633)	(1966)	(3833)	(7488)	(100)
Other medical surgical patients												
Cost per day, \$	713	793	680	647	748	639	696	752	680	725	810	674
No. of hospitals responding	164	48	116	43	3	40	49	11	38	48	18	30
Charge per day, \$	915	885	927	892	749	902	914	897	920	841	718	909
No. of hospitals responding	171	48	123	45	3	42	51	10	41	50	18	32
Revenue per day, \$	687	662	696	603	429	613	687	622	703	704	679	718
No. of hospitals responding	157	46	111	39	2	37	44	9	35	51	19	32
(Loss)-gain per day, \$	(26)	(131)	16	(44)	(319)	(26)	(9)	(130)	23	(21)	(131)	44

\*AIDS indicates acquired immunodeficiency syndrome.

Table 8.—Average Outpatient Costs, Charges, and Revenues by Ownership and Location

	Overall			Northeast			Midwest			South		
	Total	Public	Private	Total	Public	Private	Total	Public	Private	Total	Public	Private
AIDS outpatients												
No. of visits*	21 933	13 487	8446	6208	0	6208	1545	1203	342	12 131	10 243	1888
No. of hospitals responding	39	15	24	8	0	8	13	4	9	10	6	4
No. of visits per patient per year	8.2	9.0	6.0	7.3	...	6.3	12.7	8.2	13.0	7.4	12.0	4.4
Cost per visit, \$	237	308	125	107	...	101	139	144	119	341	366	204
Cost per patient per year, \$	1943	2772	750	781	...	636	1765	1181	1547	2523	4392	898
Charge per visit, \$	287	368	158	129	...	129	143	146	135	415	455	254
Charge per patient per year, \$	2353	3312	948	942	...	813	1816	1197	1755	3071	5460	1118
Revenue per visit, \$	63	44	104	58	...	56	96	90	118	64	36	212
Revenue per patient per year, \$	517	396	624	423	...	353	1219	738	1534	474	432	933
(Loss)-gain per visit, \$	(174)	(254)	(94)	(49)	...	(45)	(43)	(54)	(1)	(277)	(330)	8
(Loss)-gain per patient per year, \$	(1427)	(2376)	(126)	(358)	...	(283)	(546)	(443)	(13)	(2050)	(3960)	35
Other outpatients												
Cost per visit, \$	130	143	119	99	96	100	125	138	118	183	182	185
No. of hospitals responding	53	25	28	11	2	9	19	7	12	13	8	5
Charge per visit, \$	143	148	140	109	93	112	132	138	129	212	169	290
No. of hospitals responding	61	26	35	14	2	12	22	7	15	14	9	5
Revenue per visit, \$	93	85	99	82	...	82	87	88	87	132	98	178
No. of hospitals responding	52	22	30	8	0	8	19	6	13	14	8	6
(Loss)-gain per visit, \$	(37)	(58)	(20)	(17)	...	(18)	(38)	(50)	(31)	(51)	(84)	(7)

\*For six hospitals, visits were estimated as average for their region-ownership category.

Total	West	
	Public	Private
12 571	11 991	580
17	11	6
788	789	1111
9929	9613	14 221
16 075	16 841	18 109
1126	1104	1495
14 188	13 800	19 136
22 970	24 178	24 369
703	692	897
8858	8650	11 482
14 341	15 155	14 621
(85)	(77)	(214)
(1071)	(963)	(2739)
(1734)	(1586)	(3488)
844	810	912
24	16	8
1109	1083	1165
25	17	8
788	694	1003
23	16	7
(56)	(116)	(91)

proportion of minorities, and a population that included more children (presumably due to the inclusion of children's hospitals among the participating associations).

There were significant differences in the race and age proportions between regions and ownership categories ( $P < .01$  for all comparisons). Public and private hospitals in the Northeast treated the lowest proportion of white AIDS patients of any categories (15% and 48%, respectively). Hospitals in the West treated the lowest proportion (24%) of minority AIDS patients of any region or ownership group.

#### FINANCIAL INFORMATION

##### Payer Source for Inpatient Admissions

Responding hospitals reported that Medicaid was the primary payer for 44% of all admissions and private insurers represented 29% (Table 5). "Self-pay" and "other," categories that generally represent uninsured or indigent patients, accounted for 23% of the admissions. Medicare was the payer for 2% of admissions.

Source of payment was found to differ across ownership and regional groups ( $P < .001$  for both ownership and region). Medicaid was a payer for significantly more AIDS admissions in western and northeastern institutions (55% and 54%, respectively). Eighteen percent of admissions to hospitals in the South were covered by Medicaid, the smallest percentage of all regions. Almost half (48%) of all admissions in southern hospitals were reported as self-pay/other admissions.

Public hospitals admitted a significantly higher percentage of PWAs whose payer source was Medicaid (52% of admissions to public hospitals vs 31% of admissions to private institutions) and a higher proportion of self-pay/other (31% vs 13% for private hospitals). Private hospitals admitted a larger proportion of patients who were privately insured (48% vs 13% for public hospitals). Eighty-three percent of the AIDS admissions in public hospitals and 47% of the admissions in private hospitals were related to what is considered predominantly low income (ie, Medicaid, self-pay, and other).

Public hospitals in the Northeast reported the highest proportion (71%) of Medicaid admissions for any hospital group. Public and private hospitals in the South demonstrated significantly higher percents of self-pay/other and fewer Medicaid admissions than any other regional group in their respective ownership categories.

##### Payer Source for Outpatient Visits

A small number of hospitals (70) provided outpatient financial information, and results from these analyses are less conclusive. For the responding hospitals, the majority of outpatient visits for PWAs were reported as self-pay (50%) and Medicaid (31%) (Table 6). Private insurance accounted for only 15% of the visits.

Payer-source proportions for outpatient services varied among the ownership and region categories ( $P < .001$ ). With the exception of the Midwest, private hospitals in each region reported a greater proportion of privately insured visits and Medicaid visits than their public hospital counterparts. Those AIDS outpatients in public hospitals were most likely not to have insurance: 57% of visits to public hospitals overall, and 70% of visits to southern public hospitals were self-pay/other. However, both public and private hospitals treated large proportions of low-income (Medicaid and self-pay) PWAs. No region or ownership group treated a proportion of privately insured AIDS outpatients greater than 24%.

##### Inpatient Costs and Revenues

Inpatient costs averaged \$681 per day (charges per day averaged \$864) while revenues averaged 80% of costs at \$545 per day (Table 7). (Hospitals were asked to specify the method they used to arrive at cost-per-day figures [ie, ratio of cost to charges and, if so, what type], or to specify another approach. Eighty-nine percent of responding hospitals reported using a ratio of cost to charges to calculate costs. The remaining 11% reported using special-cost studies, chart review, or similar methods of arriving at costs per day. Median values for cost, charge, and revenue did not differ greatly from the mean figures, with median cost per day at \$651, median charge per day at \$824, and median revenue per day at \$584.) Inpatient costs per patient per year (cost per day  $\times$  number of days per patient per year) averaged \$17 910; per admission costs (cost per day  $\times$  ALOS) were \$11 441. Costs per patient per year by region ranged from \$14 410 in the South to \$20 661 in the Northeast. Public hospitals in the Northeast reported the highest costs per patient per year of any institutional group (\$26 682). Hospital revenues averaged \$14 334 per patient per year and \$9156 per admission.

Comparing financial information for AIDS patients and other medical/surgical patients yielded no significant differences for costs, charges, and revenues. However, losses (cost - revenue) per

Total	West	
	Public	Private
2049	2041	8
8	5	3
9.5	9.5	9.1
112	111	291
1064	1055	2648
112	111	451
1064	1055	4104
53	52	336
504	494	3058
(59)	(59)	45
(561)	(561)	410
106	120	44
10	8	2
122	146	60
11	8	3
63	69	45
11	8	3
(43)	(51)	1



Table 9.—Changes in Hospital Utilization: Teaching Hospitals

	Northeast				Midwest				South			
	Public		Private		Public		Private		Public		Private	
	1985	1987	1985	1987	1985	1987	1985	1987	1985	1987	1985	1987
No. of hospitals responding	15	18	31	53	12	16	20	44	15	18	16	28
No. of patients												
Total	1734	2951	1194	3772	151	469	91	919	506	1861	258	1329
Average per hospital	116	164	39	71	13	29*	5	21†	34	103	16	47*
No. of admissions												
Total	2170	4238	2366	5682	274	702	129	1599	760	2632	629	2422
Average per hospital	145	235*	76	111	23	44*	6	36†	51	146	39	87
No. of admissions per patient per year	1.3	1.4†	2.0	1.6†	1.8	1.5	1.4	1.7	1.5	1.4	2.4	1.8
No. of inpatient days												
Total	58174	103730	45600	107203	4661	9617	2649	20723	12612	36131	7536	32107
Average per hospital	3878	5763	1471	2023	388	601	132	471†	841	2007	471	1147
Average length of stay, d	26.7	24.5	19.4	16.2	16.9	13.7	22.0	13.1	16.5	13.7†	12.1	13.2
Average No. of days per patient per year	33.4	35.1	37.7	28.5†	29.8	20.7	26.4	22.4	24.7	19.5*	29.4	24.4

\*Comparisons of 1985 and 1987 means via *t* tests resulted in significant differences at *P* < .05.†Comparisons of 1985 and 1987 means via *t* tests resulted in significant differences at *P* < .01.

Table 10.—Risk-Group and Demographic Changes: Teaching Hospitals

	Northeast				Midwest				South			
	Public		Private		Public		Private		Public		Private	
	1985	1987	1985	1987	1985	1987	1985	1987	1985	1987	1985	1987
No. of patients*	1741	3018	1468	3133	128	379	94	666	463	2649	227	1111
No. of hospitals responding	15	17	30	45	12	14	20	36	14	17	14	22
Risk groups, %												
Homosexual	18	18	56	63	75	73	80	78	66	57	79	77
Homosexual IV drug user	5	6	5	3	10	10	6	5	6	10	9	4
Heterosexual IV drug user	66	65	31	25	11	9	4	7	12	13	4	9
Sex partner of risk-group member	4	4	2	4	0	3	2	2	6	2	1	2
Child of risk-group member	5	5	4	1	0	1	0	1	7	14	2	4
Blood-product related	1	1	2	3	3	5	8	6	3	5	5	4
Age, y (%)												
0-2	7	3	2	1	1	1	0	1	2	8	1	1
3-19	1	1	2	1	2	0	1	1	1	1	3	3
20-49	88	89	93	89	94	93	93	91	96	90	93	88
50+	4	6	3	9	3	6	6	8	2	1	3	8
Sex												
Male, %	80	75	84	87	97	93	95	94	89	83	95	92
Race, %												
W	12	15	50	48	60	61	83	74	48	43	64	59
B	50	52	27	30	30	32	15	18	35	41	30	36
Hispanic	33	30	22	21	7	6	1	5	16	15	3	3
Other	5	3	1	2	3	1	1	4	1	1	3	1

\*Due to differences in item response rate, the number of patients represented in each category is not identical. IV indicates intravenous.

† $\chi^2$  comparisons of proportions from 1985 to 1987 resulted in significant differences at  $\chi^2$  < .05.‡ $\chi^2$  comparisons of proportions from 1985 to 1987 resulted in significant differences at  $\chi^2$  < .01.

AIDS patient, at \$136 per patient per day, were significantly greater than other medical/surgical losses at \$26 per day (*P* < .01).

There were no overall statistically significant differences in cost per day or revenue per day by ownership. However, average public hospital losses (\$218 per day) were significantly higher than average private institution losses (\$92 per day) (*P* < .001). Cost per day and

charge and revenue differences between public and private hospitals within the regions were found generally not to be significant, with several exceptions as follows: cost per day for public hospitals in the Northeast was significantly higher than private hospital cost per day (*P* < .05); in the South, revenues per day for public hospitals were significantly lower (\$232) than those of private hospitals (\$687) (*P* < .001) and losses per

day were significantly higher for public hospitals (\$386 vs \$4 for private hospitals; *P* < .001).

Almost all comparisons of cost per day, revenue per day, and loss per day of public hospitals in the South with public hospitals in other regions demonstrated significant differences (*P* < .05). Other differences among public hospitals were not found to be statistically significant.

West			
Public		Private	
1985	1987	1985	1987
22	21	6	7
888	1653	325	527
40	79	54	75
1556	2913	453	635
71	139	76	91
18	18	14	12
21703	36209	5550	8657
967	1724	925	1237
13.9	12.4	12.2	13.6
24.7	21.8	17.1	16.5

West			
Public		Private	
1985	1987	1985	1987
526	1025	279	223
18	13	6	6
88	77	82	82
5	10	12	5
5	6	1	1
1	3	1	2
0	0	0	1
10	4	2	9
0	0	0	1
1	1	0	5
96	92	96	82
3	7	4	13
95	94	99	97
69	75	87	73
15	10	2	11
9	12	8	10
6	2	3	5

Private hospitals demonstrated no differences across regions, with one exception. Private institutions in the Northeast recorded significantly lower revenues per day than private hospitals in the South (\$510 vs \$687 for private hospitals in the South,  $P < .001$ ), and they incurred greater losses per day (\$126 vs \$4,  $P < .001$ ).

For public hospitals as a group, as well as for private hospitals, losses were

significantly greater for AIDS patients than for other medical/surgical patients ( $P < .01$  for both). Public hospitals in the South lost more on AIDS patients than on other patients ( $P < .05$ ) as did private hospitals in the Midwest ( $P < .05$ ).

#### Outpatient Costs and Revenues

Outpatient costs per visit averaged \$237 (charges = \$287), while revenues, at \$63 per visit, represented 27% of costs (Table 8). This ratio was much lower than the revenue/cost-per-visit average for other (non-AIDS) outpatient services (\$93/\$130, or 72%). Costs per patient per year for outpatient services averaged \$1943 and revenues were \$517.

Public hospitals' average cost per outpatient visit was significantly higher than private hospitals' average cost ( $P < .01$ ). Public hospitals' average revenue per visit represented 14% of costs, compared with private hospitals' revenues, which represented 83% of costs. The resulting losses per visit (\$264 for public hospital visits and \$94 for private hospital visits) were significantly different ( $P < .01$ ).

#### Total Service Costs and Revenues

Fifty-four percent (148) of hospitals responding to the survey provided inpatient cost, charge, and revenue information, representing 144 478 inpatient days. Fourteen percent (39 hospitals) provided similar data for outpatient treatment, representing 21 933 visits. Hospitals reporting inpatient costs, charges, and revenues were not significantly different on the basis of number of beds, ALOS, and days per patient per year when compared with hospitals that responded to the survey but did not report financial information. While the former group of hospitals reported fewer inpatient days and fewer patients treated ( $P < .05$  for both), we found no correlation between these variables and costs or revenues. Thus, these results of the comparisons of hospitals reporting and not reporting financial information support the application of these cost estimates to the larger survey group. Based on these results, we estimate that the costs for inpatient care for the 27 126 AIDS patients alive during 1987 were \$486 million; the costs for outpatient care were \$53 million.

#### CHANGES IN HOSPITAL CARE FOR AIDS PATIENTS: 1985 AND 1987

To examine hospital care for AIDS patients over time, we compared the public and private hospitals belonging to the National Association of Public Hospitals and the Association of American Medical Colleges' Council of Teach-

ing Hospitals that responded to our 1985 survey (excluding Veterans Administration hospitals) and the members from these associations who responded to the 1987 survey. Because of the relatively small group of hospitals included, some regional and ownership groups are not adequately represented. Also, with few exceptions the comparison group is composed of teaching institutions. Therefore, the information is presented for each region and ownership category, and is not aggregated in regional or national totals. Our analysis of the reported information indicated that teaching hospitals experienced changes in patterns of utilization and financing between 1985 and 1987. Public hospitals in the Northeast reported the highest average number of AIDS patients treated in 1987, 41% above their 1985 caseload (Table 9). However, public and private hospitals in the Midwest and the South reported the greatest increases between 1985 and 1987: in the Midwest, private hospitals increased 320% and public facilities increased 123%; in the South, private hospitals increased 194% and public hospitals increased 203%.

Variation in the ALOS and days per patient per year did occur by ownership within regions. Change in ALOS ranged from a 12% increase among private hospitals in the West to a 41% decrease among private institutions in the Midwest. Change in the days per patient per year ranged from a 5% increase in public hospitals in the Northeast to a 31% decrease among public hospitals in the Midwest. Slight increases occurred for the majority of hospital groups for risk-group categories other than homosexual (Table 10). The public institutions in the West and South experienced the greatest proportionate decline in homosexual PWAs, 11% and 9%, respectively. Public hospitals in the Northeast reported virtually no risk-group change during the 2 years.

With the exception of public hospitals in the West, all ownership categories experienced an increase in black PWAs, with the private hospitals in the West and public and private institutions in the South reporting the largest increases (range, 5% decrease in public hospitals and 9% increase in private hospitals in the West). Other changes in racial/ethnic groups were not as consistent.

Analysis by ownership within and across regions revealed substantial variation in payer-source changes (Table 11). Private institutions in the Northeast reported the largest increase in privately insured AIDS admissions (16%) and the greatest decreases in Medicaid and self-pay/other (6% and

Table 11.—Changes in Payer Source: Teaching Hospitals

	Northeast				Midwest				South			
	Public		Private		Public		Private		Public		Private	
	1985	1987	1985	1987	1985	1987	1985	1987	1985	1987	1985	1987
No. of admissions	2903	3846	959	4498	1003	525	95	1434	482	2587	201	1383
No. of hospitals responding	13	17	28	44	11	12	19	40	14	18	15	23
Payer source, %												
Medicaid	69	72	44	38	50	46	27	31	17	18	14	16
Private insurance	6	10	30	46	32	24	47	50	8	12	62	58
"Self pay"/"other"	18	13	22	10	12	21	9	16	71	68	22	24
Medicare	1	2	4	2	5	4	2	3	2	2	1	3
Prisoner	8	4	0	4	1	5	14	0	3	2	1	0

\* $\chi^2$  comparisons of proportions from 1985 and 1987 resulted in significant differences at  $\chi^2 < .05$ .† $\chi^2$  comparisons of proportions from 1985 and 1987 resulted in significant differences at  $\chi^2 < .01$ .

Table 12.—Changes in Costs and Revenues: Teaching Hospitals

	Northeast				Midwest				South			
	Public		Private		Public		Private		Public		Private	
	1985	1987	1985	1987	1985	1987	1985	1987	1985	1987	1985	1987
No. of hospitals responding	1	4	12	30	6	8	9	25	7	12	9	17
AIDS inpatient care, \$												
Cost per day	612	705	638	692	574	774	707	742	618	604	667	714
Cost per admission	16340	17273	12377	12594	9701	10604	15554	9720	10164	8275	8071	9425
Cost per patient per year	20441	24746	24053	19722	17105	18022	18665	16621	15215	11778	19610	17422
Revenue per day	600	651	539	502	256	536	801	669	203	216	525	726
Revenue per admission	18020	15950	10457	9136	4326	7371	17622	8764	3350	2959	6353	9563
Revenue per patient per year	20040	22850	20320	14307	7629	11137	21146	14986	5014	4212	15435	17714
(Loss)-gain per day	(12)	(54)	(99)	(190)	(318)	(236)	94	(73)	(413)	(386)	(142)	12
(Loss)-gain per admission	(320)	(1323)	(1921)	(3458)	(5374)	(3233)	2068	(956)	(6815)	(5316)	(1718)	158
(Loss)-gain per patient per year	(401)	(1895)	(3732)	(5415)	(8476)	(4885)	2482	(1635)	(10201)	(7566)	(4175)	293
Other medical/surgical patients, \$												
Cost per day	565	748	517	652*	602	752*	578	668	513	795	653	871
Revenues per day	600	428	555	631	518	622	509	727†	423	695	577	733
(Loss)-gain per day	35	(319)	38	(21)	(84)	(130)	(69)	59	(90)	(100)	(76)	62

\*Comparisons of 1985 and 1987 per day means via  $t$  tests resulted in significant differences at  $P < .05$ .†Comparisons of 1985 and 1987 per day means via  $t$  tests resulted in significant differences at  $P < .01$ .

Note: The very small number of cases in some cells makes significance testing difficult. Differences may exist in other cells that cannot be measured with small numbers of cases.

12%, respectively). Public hospitals in the Northeast experienced much less variation by payer source, although they did report slight increases in Medicaid admissions (3%) and privately insured admissions (4%) and a small decrease (5%) in self-pay/other admissions. Public and private institutions in the Midwest reported some of the largest increases in self-pay/other admissions (9% and 7%, respectively). Public hospitals in the South reported a slight decrease (5%) in self-pay/other admissions. Western public hospitals showed little change by payer source, maintaining a high concentration of Medicaid and self-pay/other admissions. However, private institutions in the West reported the greatest decrease (29%) in privately insured admissions and the largest increase (10%) in self-pay/other admissions. Medicare

PWA beneficiaries represented one of the lowest proportions, but demonstrated modest increases in certain areas (eg, the West).

Our 1985 to 1987 comparative analysis of financial characteristics for teaching hospitals included only those institutions providing both costs and revenues in both years (Table 12). The very small number of respondents in some categories (especially the private hospitals in the West and public hospitals in the Northeast) require that caution be used in interpreting the figures. They are presented to give some insight into what is happening for a small set of hospitals, but should not be considered representative of all hospitals in those regions.

Financial support and costs also varied by ownership within and across regions. The smallest changes in cost per day and per inpatient per year occurred among public hospitals in the South,

where costs actually decreased slightly (-2% in cost per day and -23% in cost per inpatient per year).

Changes in losses per day and per inpatient per year were mixed. The highest percentage increases in losses for these two measures occurred among the private institutions in the West and public institutions in the Northeast (434% and 350%, respectively, for losses per day; 423% and 373%, respectively, for losses per inpatient per year). The greatest decrease in losses occurred among private institutions in the South (108% decline in losses per day and a 107% decrease in losses per inpatient per year). Public hospitals in the Midwest and South also reported decreases in losses.

#### COMMENT

Our results reveal a major concentration of PWAs in a relatively few institutions. These hospitals tend to be larger



West			
Public		Private	
1985	1987	1985	1987
1283	2664	431	422
21	20	6	6
		†	
59	59	25	42
14	14	68	36
26	24	4	14
2	3	3	5
0	0	0	0

West			
Public		Private	
1985	1987	1985	1987
16	10	1	1
650	833	504	885
9035	10 329	6149	12 036
16 055	18 159	8618	14 803
500	655	566	671
6950	8122	6930	9126
12 350	14 279	9713	11 072
(150)	(178)	64	(214)
(2065)	(2207)	781	(2910)
(3706)	(3680)	1094	(3531)
710	804	771	834
617	668	869	928
(93)	(136)	98	94

than the average community-based hospital. Still, with fewer than 5% of hospitals involved in treating more than 50% of the identified AIDS cases, and with a large concentration of patients in a subset of these hospitals, any changes in financing or treatment patterns are likely to affect these hospitals most significantly. Of particular concern is that, if current trends prevail, the generally inner-city hospitals where AIDS patients are concentrated may find their ability to provide health services in general severely compromised. Moreover, it may become more difficult to draw broader political and community support for increased resources from areas and providers not influenced by the epidemic.

All hospital groups reporting here have experienced increases in their AIDS caseloads. However, the characteristics of the patient population treated in these institutions appears to be changing. For many hospitals, minor-

ities represent the majority of AIDS patients treated. Also, with the exception of the Northeast, our findings confirm the CDC's 1985 to 1987 report of a pattern of emerging risk-group diversity across regions (J. Buehler, CDC, personal communication, January 26, 1989). Southern hospitals, especially public institutions, appear to be developing patient profiles that more closely resemble the Northeast (ie, higher proportions of intravenous drug users and children of risk-group members who tend to be low income and/or uninsured). If these patterns truly presage the future HIV-infected populations, efforts directed at prevention, diagnosis, and treatment must be diversified to cope with the broad spectrum of needs distinctive for each subgroup. Acquired immunodeficiency syndrome may become increasingly a disease of the poor and the traditionally medically disenfranchised.

Conclusions from the 1985 to 1987 teaching hospital comparison analysis, while tentative, identified increases in the numbers of AIDS cases irrespective of location. The substantial proportionate increases among institutions in the Midwest and South confirmed the CDC determination that the epidemic is spreading throughout the country. We believe hospitals in the Northeast and West, which in the aggregate already treat the highest numbers of AIDS patients per institution, have not seen similar proportionate increases in large part because many of these providers are already inundated. For example, many public hospitals in the Northeast, which as a group averaged 164 AIDS patients per facility and experienced the highest number of days per patient per year, are already exceeding their ability to provide care.

The decline in ALOS and in days per patient per year from 1985 to 1987 that occurred for teaching hospitals in almost all regions may reflect therapeutic advances that allow outpatient treatment, some success in reducing inappropriate stays, and some progress in using alternative settings. Still, hospital days per year did increase in the public teaching institutions in the Northeast. That increase may be related to patient-population sociodemographic factors, severity of illness, and difficulty in placing their persons with AIDS in alternate-care settings.<sup>13</sup> If providers in other regions eventually face similar circumstances as the epidemic progresses, they can expect to encounter more difficulty in reducing their dependency on inpatient care.

Our estimated annual inpatient costs for AIDS, \$486 million, are lower than

most national estimates. This amount is based on costs rather than charges and does not include physician fees. Our estimates assume that patients received all of their care during the study year at the same hospital. We are understating the number of patient days and, thus, the costs, if a number of patients received inpatient care at more than one hospital. Patient information in our survey may include a small number of duplicates, where a patient received care at more than one hospital, and both hospitals responded to the survey. This type of duplication should account for a very small number of cases, because our survey includes a small proportion of all US hospitals.

We believe that regional variations may be a more important factor in explaining some of the differences in cost estimates. The great variation in cost figures from one region to the next illustrates the importance of using a national database in calculating national cost estimates. For example, according to our study, national estimates of annual AIDS inpatient costs could vary from \$713 million, if based on hospitals in the Northeast, to \$391 million, if averages of hospitals in the South are used. (An alternative estimate of the national cost of AIDS inpatient care was calculated using each region's average cost per patient per year multiplied by an estimate of the number of patients alive during the year in that region and resulted in an estimate of \$473 343 000. This estimate attempts to ensure the most appropriate regional representation in the national estimates.) Charges also vary substantially as do cost-to-charge ratios by region (range, from 70% in the West to 83% in the Northeast among reporting hospitals). Moreover, we have documented that hospitals in the South and Midwest are beginning to treat significantly more AIDS patients than before. Hospitals in these regions also reported some of the lowest costs per patient per year.

All categories of hospitals, without exception, did not meet their costs of treating AIDS patients. However, the extent of those losses did vary across hospitals, apparently affected by Medicaid as a payer and by the proportion of care provided to low-income patients. Where Medicaid inpatient coverage tended to be more expansive, such as in the Northeast and West, private institutions, in general, treated a greater number of low-income PWAs and a lower proportion of privately insured than their counterparts in other regions. For private institutions in the Northeast, this situation contributed to a loss of more than \$200 000 per facility for 1987,



contrasted with private institutions in the South, which lost \$3100 per facility. Although the small response group limits our 2-year comparison, it suggests that private institutions in the West may also have increased their low-income PWA caseload proportion substantially and may have sustained higher losses between 1985 and 1987. Such findings reflect a willingness on the part of private hospitals to accept more low-income AIDS patients if they are able to receive some compensation through Medicaid.

Public hospitals treated the largest proportions of low-income AIDS patients across all regions. They also lost more per patient per year than the private hospitals in their regions with the exception of the West, where private hospitals reported the highest cost per day. In the Northeast, where the low-income PWA numbers were the largest and the number of inpatient days the greatest, the average public hospital lost more than \$600 000 in 1987. Our 1985 to 1987 comparison confirmed some of the largest increases in losses for this region's public teaching institutions. In this case, the sheer volume of care rendered by these institutions created major financial losses despite relatively higher inpatient Medicaid coverage of PWAs per day. In the South, where state Medicaid programs have tended to be the most restrictive, AIDS treatment continues to be a financial disaster for public hospitals. Although we found some indication that marginal progress was made in reducing public teaching institution losses between 1985 and 1987, overall, public hospitals in the South also lost more than \$600 000 per facility during 1987.

Two policy implications emerge from these conclusions. First, without an equitable distribution of the burden of care for low-income PWAs, hospitals with a disproportionate share of these patients face an economic crisis. And second,

Medicaid standards of coverage must be applied with more equanimity throughout the country. The grim situation we describe in the South and Northeast represents what could happen on a broader scale if Medicaid support does not keep pace or if private insurers or the private sector reduce their support. Moreover, the alarming losses due to financial shortfalls and the growing volume of care reinforce the need for adequate reimbursement and for more effective alternatives to inpatient treatment if we are to avoid desperate measures such as rationing care.

Our results relating to outpatient financing must be considered with caution since a limited number of hospitals provided complete information for this analysis. For example, we believe our determination of average cost per visit, \$237, underestimates true outpatient costs since that amount is substantially lower than per visit costs for therapy with zidovudine alone. Our study does suggest that AIDS hospital-based outpatient care is much more dependent on public-sector support than inpatient care, with private hospitals relying on Medicaid and public hospitals treating a much larger proportion of charity-care patients (ie, self-pay and other). The low proportion of privately insured PWAs suggests that with more freedom to choose providers these individuals may be using private physicians and clinics for their outpatient care.

We may find that private hospitals will monitor Medicaid reimbursement levels and utilization for PWAs and will be very reluctant to expand outpatient care if public payers decrease coverage. Public hospitals, which lost 86 cents on every \$1 of outpatient costs, compared with 30 cents per \$1 of costs for inpatient care, cannot tolerate such low outpatient reimbursement rates for long without adverse effects in other patient-care sectors. With little financial incentive, especially among public hos-

pitals, to encourage outpatient hospital care for PWAs, promising early efforts to reorient care to settings other than the inpatient unit are likely to remain unfulfilled.

Many questions cannot be addressed by our study. We are limited by our focus on the hospital as the unit of analysis rather than the patient, and by the lack of data on the vast numbers of other HIV-infected individuals not yet afflicted with AIDS, but who have challenging health care needs. However, our investigations and other attempts to describe the broader scope of hospital care can complement important patient, institution, or locally based research at other levels. Collaboratively, these "macro" and "micro" level studies can shed light on a number of critical questions, including the financial costs and revenues related to payment source; costs of treating PWAs from different risk groups; the effect of changes in patterns of care (eg, case management and dedicated AIDS units) on cost reductions; monitoring the changing costs of all health care for a patient with AIDS; and assessing hospital and health care costs for all HIV-infected individuals. As we enter the 1990s, these cooperative efforts will be essential if we are to make informed and humane decisions for care of persons with AIDS.

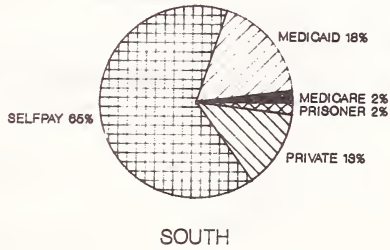
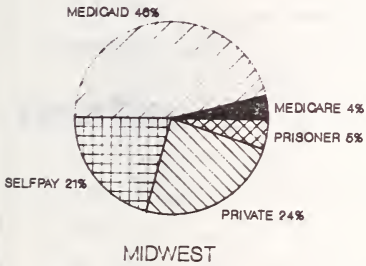
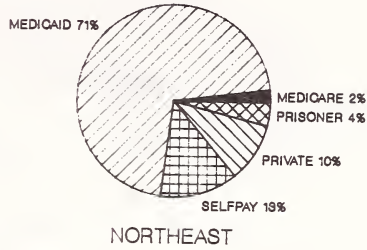
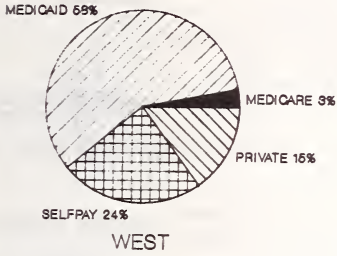
We would like to thank and acknowledge the following organizations and individuals: The Robert Wood Johnson Foundation, Princeton, NJ, and the National Center for Health Services Research, Rockville, Md, for their financial support; James Bentley, PhD, of the Council of Teaching Hospitals; John Harty, JD, of the National Council of Community Hospitals and Robert Sweeney of the National Association of Children's Hospitals and Related Institutions for their participation and assistance in this project; Ron Brookmeyer, PhD, of Johns Hopkins University, Baltimore, Md, for his statistical support; Elizabeth Hintz, MA, of National Public Health and Hospital Institute, Washington, DC, for her research assistance; and the administrators and staff at the hospitals participating in our study.

## References

1. HIV/AIDS Surveillance Report. Atlanta, Ga: Centers for Disease Control; July 1989.
2. Scitovsky A, Cline M, Lee P. Medical care costs of patients with AIDS in San Francisco. *JAMA*. 1986;256:3103-3106.
3. Seage G, Landius S, Barry A, et al. Medical costs of AIDS in Massachusetts. *JAMA*. 1986;256:3107-3109.
4. Berger R. Cost analysis of AIDS cases in Maryland. *Med J*. 1986;34:1173-1175.
5. Bloom D, Carliner G. The economic impact of AIDS in the United States. *Science*. 1988;239:604-610.
6. Hellingier F. Forecasting the personal medical care costs of AIDS from 1988-1991. *Public Health Rep*. 1988;103:309-319.
7. Pashal A. *The Costs of Treating AIDS Under Medicaid: 1986-1991*. Santa Monica, Calif: RAND Corp; 1987.
8. Scitovsky A, Rice D. Estimates of the direct and indirect costs of acquired immunodeficiency syndrome in the United States, 1985. *Public Health Rep*. 1987;102:5-18.
9. Scitovsky A. The economic impact of AIDS. *Health Aff (Millwood)*. 1988;7:32-45.
10. Graves E. *Utilization of Short-Stay Hospitals by Patients With AIDS: United States, 1984-1986. Advance Data*. Hyattsville, Md: National Center for Health Statistics; May 24, 1988. No. 156.
11. Andrus D, Beers V, Bentley J, et al. The provision and financing of medical care for AIDS patients in US public and private teaching hospitals. *JAMA*. 1987;258:1343-1346.
12. Kelly J, Ball J, Turner B. Duration and costs of AIDS hospitalizations in New York: variations by patient severity and hospital type. Presented at the IV International Conference on AIDS; June 15, 1988; Stockholm, Sweden.

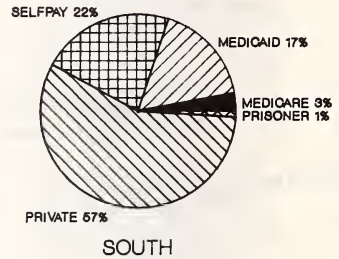
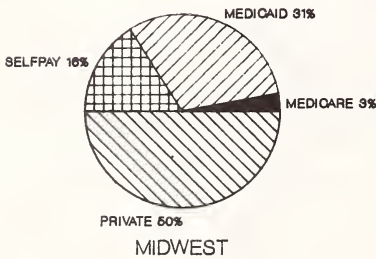
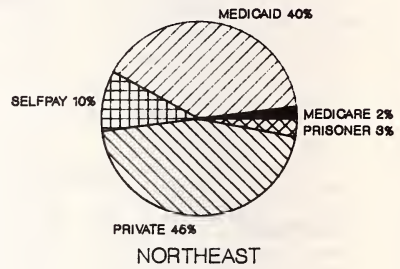
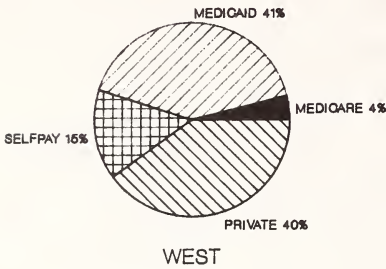
# PAYER SOURCE FOR PUBLIC HOSPITALS

## 1987



Source: Andrulis D, et al. "The 1987 U.S. Hospital AIDS Survey" JAMA, Vol 262, August 11, 1989 p 784-794.

## PAYER SOURCE FOR PRIVATE HOSPITALS 1987



Source: Andrulis D, et al. "The 1987 U.S. Hospital AIDS Survey" JAMA, Vol 262, August 11, 1989 p 784-794.

## American College of Emergency Physicians

# 1989 CHAPTER SURVEY ON HOSPITAL AND EMERGENCY DEPARTMENT OVERCROWDING

• States reporting overcrowding problems: 41

• States reporting no overcrowding problems: 9

*Idaho*  
*Minnesota*  
*Nebraska*

*New Hampshire*  
*New Mexico*  
*North Dakota*

*Oregon*  
*Utah*  
*Wyoming*

• Contributing factors:

1. Shortage of health professionals (primarily nurses)
2. Increased use of emergency departments for hospital admissions
3. High inpatient average daily census
4. More poor/uninsured patients
5. Hospital bed reductions
6. Emergency department standby/diversion status
7. Shortage of nursing home beds/home care
8. Hospital closures
9. Emergency department closures
10. AIDS patients
11. High average length of hospital stay



From the New York Times, December 19, 1988

## *Emergency Rooms Overwhelmed As New York's Poor Get Sicker*

By HOWARD W. FRENCH

Overwhelmed by patients suffering from AIDS, drug abuse and a poverty-related deterioration in health, New York City's emergency rooms are increasingly unable to provide acute care and are coming to resemble ill-staffed inpatient wards, health care experts say.

With most hospitals short of inpatient beds, and with few alternatives to hospitalization to free them up, experts say, emergency rooms in public and private hospitals have been transformed into wards, where beds are moved in to accommodate the sick, aged, and homeless, often at the expense of accident, stroke and heart attack victims and others needing immediate care.

Dr. Lewis Goldfrank, director of emergency medicine at Bellevue Hospital Center, said during a recent conference on the problem that patients

"are crowding into our corridors, our waiting rooms and our treatment areas such that normal care for those with minor problems is greatly delayed. Patients with heart attacks and strokes wait often 12 to 36 hours to get into intensive care units.

"Over the last six months most of our hospitals have faced changing census patterns that make bed accessibility for the next patient impossible."

Dr. Robert P. Wyman, acting medical director of emergency services at Montefiore Medical Center in the Bronx, said: "What we are seeing now, a year and a half ago we would have said: 'We could never cope with that.'"

Last month, Dr. Wyman said, a 92 percent occupancy rate at Montefiore — unheard of in most hospitals elsewhere in the country — and an unrelenting crush of emergency patients forced his staff to hold a total of 700 patients in the emergency room for at least one night apiece. Only two years ago, he said, his emergency room would normally have had from 1 to 10 "overnighters" a month. While it has been customary for those with minor injuries to wait long hours for care,

# As Poor Get Sicker, Emergency Rooms Are Swamped

(Continued From Page A1)

many of these patients, doctors recognize, have a medical need for urgent attention.

The crowding is placing far more strain on hospital staffs and resignations among nurses are accelerating at a time when the need for them is greater and there is a nationwide shortage of them.

Emergency rooms in Los Angeles, Miami, Fort Worth and other cities with many illegal immigrants or indigents living under difficult circumstances without regular medical care, are under similar pressures. Patients are often backed up for hours or days awaiting care.

## City Is Getting Sicker

In New York, experts say, the root of the problem is that the city's patient population is becoming sicker and sicker, a consequence of a rapidly growing poor population and the twin epidemics of AIDS and crack. The percentage of New York City residents living below the Federal poverty level has grown from 15 percent in 1973 to 24 percent in 1984, according to United States Census Bureau data.

The average hospital stay in the city increased to 9.8 days this year from 8.2 days in 1987, continuing an upward trend of the last few years.

With a larger chronically ill population staying longer in hospitals, inpatient beds for admissions needed to relieve pressure on emergency rooms have grown scarcer and scarcer.

The situation is aggravated by a lack of alternatives to hospitalization, like primary care and nursing homes.

At Booth Memorial Hospital in Flushing, Queens, Dr. Mary Jo Morganti, an emergency room attending physician, said "It is not uncommon for us to have four or five patients sitting in wheelchairs" because beds are not available.

## 'Slots 7, 7½, 7¼'

"We have 12 slots," she said, pointing to the curtained treatment bays of the hospital's modest emergency room. "They are supposed to be individual, but because of the need we have started breaking them down into Slots 7, 7½, and 7¼," she said, gesturing toward doubled-up patients.

In the hallways outside, others whose needs placed fewer demands on the overstressed emergency room lay on stretchers, some in pain, others merely afraid, as they awaited a turn in a regular bed.

Hospital administrators and emergency room doctors point to this kind of overflow as the most obvious and perhaps the most painful symptom of the city's larger hospital crisis.

"As our ability to transfer patients to inpatient wards or to other hospitals has declined, the length of stay in the emergency room has gone up," said Dr. Mark C. Henry, director of emergency medicine at Booth Memorial.

"Some people come in with abdominal pain and fever and wait until they decide they can't wait any longer," Dr. Henry said. "These are patients we would have liked to see."

## Crowding Risks Infection

In addition to the problem of patients with potentially serious problems abandoning their quest for care in the face of long waits, doctors at many hospitals point to the risks of infection posed by crowding the sick together.

"We are looking at ways to reduce length of stays," said Dr. Garret M. Gordon, deputy medical director at Montefiore, "but we are getting much sicker patients — people who present with

## Inpatient beds are becoming scarcer.

multiple systems failures," he said, were hard to treat and drained hospital resources.

To cope with the crisis, Montefiore, like nearly every other hospital that serves as a 911 or trauma center, is engaged in a frenzied recruitment search to beef up a staff steadily eroded by the attrition caused by emergency room burnout.

"Few areas of the hospital have experienced the kind of resignations we have," said Susan H. McQueen, administrative nurse supervisor of the emergency room. "With our absolutely overwhelming number of patients, nurses have just begun to burn out, and our staffing needs have skyrocketed."

To cope with the growing workload, the number of nurses assigned to the emergency room has been increased to between 36 and 50 from 18 only two years ago. The change has come despite an extremely short supply of skilled nurses throughout the city and state.

Many hospitals, unable to recruit enough nurses, have responded by pay-

ing nurses from other operations lucrative overtime and per-diem wages. Health care professionals say this has led to a new set of problems.

"These nurses are not familiar with the policies and procedures of the hospital, and the staff nurses complain that often they are more of a hindrance than a help," said Dr. Henry of Booth Memorial. "You want experienced people there, not people learning on the job, when you are trying to treat the sickest patients."

Many of the city's 11 acute care municipal hospitals, which often treat New York's poorest patients, have long suffered the emergency room conditions that are proliferating in the rival private sector.

Lacking the resources of the voluntary hospitals and generally perceived by professionals like nurses, X-ray technicians, and pharmacists as less desirable places to work, many of the city's municipal hospital emergency rooms have been unable to keep up in the competition to recruit and retain skilled staff.

## Holding Line at King's County

At the mammoth 1,284-bed King's County Hospital in Brooklyn, which has one of the country's busiest and most antiquated emergency rooms, the number of nurses on duty has remained fairly constant throughout the crisis.

Instead of adding nurses as some other hospitals have been able to do, the emergency nursing director at King's County, Jean Morello, has had to rely on per-diem nurses merely to hold the line against staff attrition.

"Our biggest problem is getting enough support staff — clerical people and nurses' aides — to fill all the slots," Ms. Morello said. On top of providing emergency care, she said, "our registered nurses have to fill out forms, answer phones, page doctors and get involved in supply problems."

King's County's nurses and doctors are stretched even further by the unorthodox layout of the hospital's emergency facilities, which are spread along a long corridor in small rooms and partitioned warrens, rather than ringed in the open-space design more common in emergency rooms that allow doctors and nurses to monitor many patients from a central command post.

"A normal ambulatory care center has about four patient visits per square foot," said Dr. Benjamin Chu, acting director of adult emergency services at King's County Hospital. "Here we have 35 visits per square foot, or 800 to 900 emergency visits a day."

"Yesterday there were 20 people in

that room and 15 in the other one over there," said Dr. Chu, pointing to separate female and male rooms — an oddity in emergency room care — where urgent but not acute care is administered, primarily to walk-in patients. "Those rooms were meant for seven patients each."

In the crowded "male room" a young tuberculosis patient sat on a chair next to a diabetic man being treated for insulin shock.

Because of space, Dr. Chu said, "We are forced to put the most immunocompromised patients in the same area with those who are most infectious."

In the female room next door, a woman who attempted suicide, a person with AIDS complaining of fever and weakness and another woman in intense pain from an undetermined abdominal malady sat huddled close together in a corner. All the beds in the suite were full. Doctors tripped over each other in the small space, and an E.M.S. team blocked the doorway, unable, for lack of a bed, to leave an elderly woman who had suffered a fall.

King's County Hospital, like other hospitals that primarily serve indigent neighborhoods, has been hard hit by an increase in patients who arrive in very poor health.

Fresh from attending to a badly injured car accident victim, Dr. Nabil Alweh, a trauma specialist, said, "Typically, an ambulance will bring in a homeless person with lacerations — and we look at him and discover he also has pneumonia and frostbite."

Emergency room doctors and nurses say the pressures of overcrowding and staff burnout are taking their toll on the quality of care they deliver.

Dr. Alweh, who has spent time providing emergency care in Beirut, said: "Our resources are so few that we had to devise a system to call on personnel from throughout the hospital to handle our problems."

"You go overboard to save a patient from trauma and there is no bed upstairs to put him in afterwards," he said. "There is something sickening about seeing conditions so bad in the richest city in the world."

## Vulnerable patients sit with infectious ones.

From the New York Times, February 15, 1989

# N.Y. Times: 2-15-89 AIDS Study: A Warning Of Epidemic In the Bronx

By BRUCE LANBERT

Testing of blood samples from some emergency-room patients at a South Bronx hospital has shown that 23 percent were infected with the AIDS virus, a finding that health officials call a disturbing sign of the extent of the epidemic.

The AIDS-antibody tests were conducted on blood initially drawn for other purposes from 143 patients who went to the Bronx-Lebanon Medical Center in July. Known AIDS patients were excluded. Positive results came back for 33 patients ranging from 13 to 71 years old.

"It's very alarming," said Dr. Jerome A. Ernst, who supervised the study and directs the Bronx-Lebanon AIDS programs. "But the alarm bells have been ringing here for years, and there has not always been someone listening."

## Similar Findings at Lincoln

The sample does not necessarily reflect infection rates among all local residents for several reasons. People going to an emergency room are, by definition, sicker than the general population. They are also, on average, poorer. Also, Bronx-Lebanon normally draws blood from half its emergency room patients, typically those being treated for cardiac, diabetic and kidney conditions, as well as bleeding wounds. Blood is not taken from a patient with an earache, a broken arm or an asthma attack.

Similar results are showing up in another South Bronx study involving several hundred patients at Lincoln Hospital, said Dr. Judith Lieberman, head of infectious diseases at Lincoln. That survey, which is under way, covers hospitalized patients and includes known AIDS cases.

The only previous AIDS testing of emergency-room patients was conducted in 1987 by the Johns Hopkins Hospital in Baltimore, according to the Federal Centers for Disease Control. That study found 119 positive results out of 1,383 samples, or 8.6 percent.

The South Bronx has one of the highest AIDS infection rates "in the country, if not the world," Dr. Ernst said, noting that Harlem and parts of Brooklyn have similarly high rates.



The New York Times/Jayne Gagliardi

Dr. Jerome A. Ernst, who supervised an AIDS study at Bronx-Lebanon Medical Center, examining a patient. "It's very alarming," he said of the results, which showed a 23 percent rate of infection among emergency-room patients tested.

Medical experts said the Bronx-Lebanon findings provided a dramatic indication of the spread of the AIDS virus in impoverished neighborhoods with rampant drug abuse. No identical emergency-room study has been conducted, but other studies have indicated that there are exceptionally high rates of infection in the South Bronx.

A statewide testing program of all newborn babies showed that in a South Bronx ZIP code, 1 in 25 mothers had the AIDS virus. The Bronx was the top county; Manhattan was a close second.

A review by the United Hospital Fund of diagnosed AIDS cases showed rates of 468 to 520 cases per 100,000 people in the Bronx-Lebanon area, compared with 86 to 96 cases per 100,000 in the northern Bronx.

A blood sampling at Bronx-Lebanon last spring found that 79 of 283 alcohol-detoxification patients carried antibodies to the AIDS virus, a rate of 27 percent. Researchers attributed that finding to drinkers' also using drugs and becoming infected from contaminated needles, or having sex with infected drug users.

## 'Community in Mind'

City Health Commissioner Stephen C. Joseph called the results of the new study "a very high number."

"I'm not surprised," Dr. Joseph said. "This virus is concentrating geographically, targeting and focusing on the poor and areas of high drug use. We

**'This virus is concentrating geographically.'**

know we are seeing increased infection and disease rates."

An epidemiologist from the Federal disease center, Dr. Michael E. St. Louis, said: "While the Bronx sample size was relatively small, what it does clearly demonstrate is that the population being served by this institution is at high risk for AIDS, clearly a community in great need."

Because of confidentiality rules, the Bronx-Lebanon specimens bore no names, and patients were not told of the findings. Data like sex and age were noted.

As part of determining the extent of AIDS infection across the nation, Federal health officials are organizing the testing of patients at 46 "sentinel" hospitals that represent a cross-section. The results will not be ready for several months.

A major new emergency-room study, involving at least 1,000 patients, is planned at the Montefiore Medical Center in the Bronx by Dr. Elie E. Schoenbaum, who has worked with Dr. Ernst.

As a general-purpose hospital, Bronx-Lebanon finds AIDS emerging in many areas, including obstetrics, pediatrics, the methadone clinic for heroin addicts, dermatology, psychiatry, home care and referrals from a nearby shelter for the homeless. The AIDS census averages 68 to 75 inpatients, occupying one-fifth of the medical-surgical beds. Sixty percent of the patients were infected through intravenous drugs, 20 percent through sex with drug users, 10 percent through homosexual activity, and 10 percent through exposure to both homosexual activity and drugs.

**'Anybody who lives here is in a high-risk group.'**

Several issues are underscored by the epidemic in the South Bronx, health experts said. One is the importance of prevention campaigns. Among the Bronx-Lebanon efforts are school presentations and an information van touring housing complexes.

"The South Bronx is a high-risk group," Dr. Ernst said. "Anybody who lives here is in a high-risk group."

## Need for Testing and Counseling

Health officials also stress the need for widespread counseling and testing. Testing enables early attention for patients, and counseling can help curb the spread of the virus. Testing has not always been easily available at hospitals, but Bronx-Lebanon is trying to help provide it.

Bronx-Lebanon is enlarging its state-authorized AIDS inpatient unit and also plans to start building in the summer an adjacent 240-bed nursing home, half devoted to AIDS patients.

The emergency-room study points up the importance of health workers' taking precautions with all patients, because some are unknowingly infected with the AIDS virus. Dr. Ernst said Bronx-Lebanon had imposed safety procedures, including the disposal of used needles and material with blood in special containers even before Federal standards were issued.

"You have to assume and treat every patient as if they're infected," the director of community health of the State Health Department, Dr. Lloyd F. Roach, said. "It's not only that emergency room, but in every emergency room in the state."



# AIDS Drives Jobs Away, Study Says

## Jammed Hospitals Raise Specter of 'a Calcutta'

By BRUCE LAMBERT

New York City's health care crisis, worsened by the epidemic of AIDS, is driving away businesses and jobs unless state and federal officials act now to relieve the overcrowded system, a privately financed commission on AIDS said yesterday.

The Citizens Commission on AIDS, financed by the Rockefeller Brothers Fund and other prominent foundations and companies, said that the economic and social costs of the epidemic citizens will have to bear and the shortages of hospital beds it is creating. "New York's standing as the center of finance and business is at stake."

"Gripped by Plague-Like Conditions"

Issuing a 136-page report, the group concluded that failure to expand services would result in limited access for both AIDS patients and other people needing hospitals, nursing homes and other health care facilities. "The mental problems are already confronting the streets because there are not enough beds in psychiatric wards, and the commission pointed out that AIDS sufferers without beds at peak are also beginning to swell the streets."

"Businesses — facing a city gripped by plague-like conditions in subways, terminals and streets — will leave for a less daunting environment," said John E. Jacob, the commission's co-chairman and the president of the National Urban League. He called this prospect "a realistic scenario. If we fail to act now."

The commission's other co-chairman, John E. Zuccotti, a former first deputy mayor, said, "The AIDS crisis is as impor-

Continued From Page B1

tant to the city's future as the fiscal crisis was in the 1960s. We are deciding whether to move to or stay in New York City. Health care is a vital component of the quality of life, the commission said. The city's rising health care costs, rising prices, taxes and utility costs have long been considered handicaps in attracting and retaining businesses. New York has been the only city in the nation where people will think twice about moving here. It's a frightening thought," J. Richard Munro, a commission member and chairman of Time Inc., said yesterday.

"Will We Step Over Bodies?"

The problem has already emerged as hospitals become overcrowded. Mr. Zuccotti, who once headed the city's planning agency and now, as a partner in the law firm Brown & Wood, often speaks out against the city's shortsighted local decisions, more and more hear people saying: "What is happening with New York's health care? Are we going to stop, or are we going to keep going?"

Curtailed health care for employees is not the only impact AIDS has on business. Health experts say companies will bear some of the brunt of the epidemic, including increased health premiums and local taxes, or, alternatively, cuts in other services.

The Citizens commission said that prompt measures, including preventing the epidemic from spreading, and homes and home care, could hold down expenses. Otherwise, the report said, "the costs of doing business will continue to escalate. While the quality of life deteriorates."

## A panel says New York is risking its lead role in commerce.

The costs of treating, housing, providing welfare and other services to AIDS patients will reach \$1.2 billion a year by 1991, the report estimated. Those costs are borne both by governments and private insurers.

"No Bold Action Has Resulted"

The commission's study is part of a state of recent AIDS plans, reports and projections from city, state and private agencies. The commission called for a shift from this planning phase to action. "The commission has urged city officials and private agencies. So far, 'no bold action has resulted' from the other plans, the commission said.

Increase the pressure, the commission will hold a conference of business executives, including Mr. Munro, and also plans to involve labor and community leaders. The commission also plans to offer this digest and critique of previous AIDS reports.

The report in May by New York City's Interagency Task Force on AIDS, did not cover state government cost estimates and has not been evaluated for follow-up.

New York State's Five-Year Interagency Plan, released last month, excluded city agencies and did not estimate, did not contain cost estimates

and used more conservative bed projections than some other plans.

The New York City AIDS Task Force, which has issued a plan that includes private as well as city facilities, but not the state, has issued most of its plan in chapters in recent months and expects to soon release cost estimates. The task force is composed of city, state and private officials, issued a report last week projecting service needs and proposing a new city-state commission to oversee AIDS services. The report was approved by Mr. Koch, but it requires state approval. Mr. Cuomo has not stated his position.

The New York AIDS Coalition, an alliance of 150 social service, health, religious and minority organizations, has been working for more money to their community AIDS programs. It did not deal with hospital or long-term care. The citizens commission was formed to coordinate AIDS planning in New York City and Northern New Jersey. Its other members are:

Sandra Feldman, President of the New York City United Federation of Teachers; Leonard Jacobs, President of the Newark Teachers Union.

Dr. David E. Rogers, chairman of New York City's Department of Health; Frederick A. O. Schwarz Jr., lawyer, a former city corporation counsel.

Joseph S. Berman, President of Atlantic City's Interagency Task Force on AIDS; Gloria Steinem, writer and founder of Ms. Magazine; Richard L. Lamm, executive director of the Lambda Legal Defense and Education Fund.

William K. Yamashiro, Principal Vice for East Asia.



From the New York Times, April 23, 1989

## Unmet needs

Huge increases in medical and social services are required if New York City is to cope with the rise in AIDS cases, a city task force has warned.

	Current services (Feb. 1989)	Projected needs	
		(Dec. 1989)	(Dec. 1993)
Hospital beds	1,746	2,200	4,020
Housing units	494*	1,200	2,940
Nursing home beds	128	900	1,228
Home care (Average daily enrollment)	n/a	1,070	3,400

\* New York City also subsidizes 1,468 renters with AIDS.

Source: New York City Office of Management and Budget; projections by New York City AIDS Task Force.

N.Y. Times; 4-23-89

# AIDS in a Deficit Year: More Plans Than Money

By BRUCE LAMBERT

NEW YORK CITY has reached a critical juncture in dealing with the AIDS epidemic. City and state decisions in the next few months may well determine whether the overstressed health care system can cope with a threefold increase in AIDS cases while continuing to serve the rest of the public.

Health care experts say they are increasingly convinced that now is the last chance to expand the system in time to deal with the projected wave of new cases. "We're at a critical point, hanging on by our fingernails," said Dr. David E. Rogers, who heads AIDS panels advising the Mayor and Governor. Kenneth E. Raske, president of the Greater New York Hospital Association, said, "We don't have the luxury of waiting another year."

This urgency is prompted by recent projections that the cumulative AIDS caseload, now 30,000, will rise to 60,000 by the end of 1993. The new patients will be depending for care on a system already so overloaded that the wealthy and powerful must go to bat for ill friends who need a hospital bed. Nursing home care, too, is in short supply; a new AIDS nursing unit at the Terence Cardinal Cook Health Care Center, the first in the

city, had 10 applicants for each of its 44 beds.

AIDS is not by any means the only health care problem in the city; some might argue that it is not even the worst, that bringing down high infant mortality rates, for instance, should have higher priority. But a system overwhelmed by AIDS cases will be even less able to deal with such complex and longstanding problems.

A cascade of recent AIDS reports, plans and projections have all called for expansion of medical and social services. "But as it stands right now," Mr. Raske said, "this is probably the biggest amount of planning for an epidemic with the least amount of action to go along with it."

Thousands of protesters have marched on City Hall and the Capitol in Albany demanding the money necessary to carry out the plans. Their campaign could not come at a worse time because of the budget problems facing all levels of government. The \$47 billion budget the State Legislature approved last week includes about \$200 million in AIDS spending; AIDS organizations are hoping to get more later in the session.

"We understand this is a tough year, but in the long run, our proposals will save money and save lives," said Robert D. Peterson, head of a coalition of nonprofit AIDS organizations.

In fact, the city, state and Federal governments are spending about \$300 million a year on

AIDS in New York City, and insurers and patients spend another \$200 million. But Gov. Mario M. Cuomo has conceded that the needs are much greater. Health care experts say that \$300 million more is needed right now to provide hospital treatment for all the people who need it and to supply the nursing homes and home care that enable those who no longer need it to get out of the hospitals. And the experts say \$1.5 billion a year will be needed by 1993.

At a time of austerity, the New York City health care system is suffering from its own deficits, layoffs and cuts in Medicare and Medicaid appropriations. Extraordinary overcrowding and understaffing is evident in every sector: public and private hospitals, nursing homes, home care, psychiatric services and drug treatment. Adding to the burden are such social ills as crack, crime, poverty and homelessness.

## 'Bad and Getting Worse'

"Things are bad and getting worse," said Mr. Raske. Reflecting the depth of discontent with the hospital system's failures, as well as other longstanding complaints, New York's largest physician organization, the State Medical Society, recently called for the resignation of the State Health Commissioner, Dr. David Axelrod.

Hopes for new coordination of state and city policies on AIDS and hospital overcrowding were dashed this month when Mr. Cuomo and Dr. Axelrod said a new city-state advisory commission was unnecessary. The proposal had come from the Mayoral Task Force on AIDS, a group of health experts, which has asked Mr. Cuomo and Dr. Axelrod to reconsider.

With that proposal stalled, New York City's business leaders have entered the fray. A small group of top executives met recently to listen to health experts' pleas for help and warnings that failure to act will render the health care system unable to care for everyone who gets sick.

The executives needed little prompting. Lewis Rudin, president of the Association for a Better New York, said his family has given nearly \$1 million to AIDS causes. He said the chief of security for his company, Rudin Management, recently had a heart attack but "couldn't get a bed for two or three days" at a hospital downtown. He was finally moved from its emergency room to an uptown hospital with a vacant bed.

Preston Robert Tisch, president of the Loews Corporation, said, "We have two very, very good friends who have AIDS. One we worked for a week to get into a hospital. The other was in the emergency room and was bleeding to death. Fortunately, I was able to get him moved into the hospital, but I think it was because my name is Tisch." New York University Medical Center was renamed Tisch Hospital this year in honor of a \$30 million gift.

Felix G. Rohatyn, the financier, called AIDS "a far more serious" challenge than the city's fiscal crisis in the 1970's, in which he played an important role as chairman of the Municipal Assistance Corporation.

The executives agreed to work with the advocates to synthesize the various AIDS reports into a single proposal to the Governor for more services and for additional taxes to pay for them. Glenn R. Michaels, director of the New York City AIDS Task Force, which helped organize the executives' meeting, said, "It's an issue of political will."

**ASSOCIATION FOR THE CARE OF CHILDREN'S HEALTH**  
Washington, DC

**Families of Children with HIV Infection – What Families are Saying**

Although the identification of HIV infection in children is a relatively recent occurrence, its impact on a child and family is similar to that of many childhood chronic illnesses. Much of the understanding that we have about the concerns of families caring for children with special health needs can be applied to these children as well.

At the same time, families of children with HIV infection have additional needs because of the circumstances surrounding their children's illness: isolation and discrimination caused by public fear and ignorance of the illness; parents and other family members may be dying or drug dependent; families may be struggling with poverty; and the broad range of needed services may not be available or accessible.

At a "Family Meeting on Pediatric AIDS" held in July, 1988, family members caring for children with HIV infection consulted with federal officials about the design of service systems that are most supportive of these children and families. Brief descriptions of the most important service system characteristics are provided below. (The meeting was sponsored by the Association for the Care of Children's Health, with support from the Bureau of Maternal and Child Health and Resources Development.)

**Families of children with HIV infection want:**

- For others to see them first as a family and, second, as a family caring for a child with complex needs. Families of children with HIV infection want recognition that they love and care about their children and, like any other family, want what is best for their children.
- **Family-centered care.** Families caring for children with HIV infection deserve and need the recognition that they are the constant in their children's lives while the service systems and personnel within those systems fluctuate. Therefore, the families should have a voice in making informed decisions about the care their children receive. This requires an assurance that families have access to complete, accurate, and ongoing information about their children's diagnoses, treatment choices, and programs.
- **Comprehensive, coordinated services.** Families of children with HIV infection are under enormous stress from the medical, physical, financial, and emotional demands of caring for their children and family. Such families need a wide array of services and support -- support that is both comprehensive and coordinated. Families benefit most when a single, identified person is available to help them find services and to provide emotional support.

- **Services that are consistent and predictable.** Currently, where a family lives largely determines the scope of services available to them. Families living in some communities have access to a wide variety of medical and support services that are both comprehensive and coordinated. Other communities offer no comparable services.
- **Services that are available to all kinds of families.** The families of children with HIV infection need an extensive range of support services and resources. Health care professionals, service providers, and the community-at-large need to recognize that these services and resources must be made available to a broad range of "families," including birth, foster, and adoptive parents and extended family members.
- **Access to support groups.** Because of shared experiences, family-to-family support groups can be a primary source of comfort and support for families caring for children with HIV infection.
- **Understanding.** Public misinformation about HIV infection and the attendant fear have devastating repercussions for families of children with HIV infection. These families often lose the support of extended family members and friends and encounter other difficulties. Their children frequently are denied admission to school and day care. Family members are often ostracized at work and at church; and they also may be treated with fear or suspicion by service providers.
- **Respect for their privacy and confidentiality.** Families caring for children with HIV infection are divided on the issue of who they should tell of their children's condition. However, these families all strongly believe that it is their decision to make.

Kennedy 10-point Action Plan for AIDS Care ServicesINITIATIVES: 1st Session, 101st Congress (1989)

1. Solidify Anti-Discrimination Safeguards for HIV infected individuals as part of Americans with Disabilities Act (ADA)
  2. Authorize and secure funding for a 3-year Low Income Treatment Assistance Program (LITAP) to provide FDA approved life-prolonging drugs to people with HIV disease;
  3. Expand and accelerate access to the most promising experimental AIDS drugs for patients with acute disease;
  4. Enable community-based organizations to actively participate in AIDS drug clinical trials and increased access to under-served individuals with HIV disease;
  5. Obtain funding for home and outpatient care under the Health Omnibus Program Extension Act of 1989; services;
- 

PROPOSED INITIATIVES: 2nd Session, 101st Congress (1990)

6. Target emergency federal relief to localities and institutions hardest hit by the epidemic.
7. Create community AIDS care consortia to plan for and deliver the full range of medical, mental health and support services to individuals and families affected by HIV disease;
8. Create transitional and supported housing for homeless people with AIDS;
9. Provide financial assistance to low-income chronically disabled individuals to enable them to pay premiums for health insurance available under COBRA which now provides a complete transition to Medicare;
10. Revitalize the National Health Service Corps and the VISTA program to assist in providing the health and social services required to deal with the dual epidemics of AIDS and drugs in both urban and rural areas.



PROGRESS REPORT ON KENNEDY PLANAIDS Initiatives: 1st Session, 101st Congress (1989)

1). Anti-discrimination protections for people with AIDS and HIV are not only just and compassionate but are the lynchpin to our ability to control the spread of HIV. The Americans with Disabilities Act was debated and passed by the Senate on September 7th with a vote of 76 - 8. This bill has the support of the President and was unanimously endorsed by the Education and Labor Committee of the House. It will receive consideration by the House of Representatives immediately following the recess.

2). LITAP is an authorization proposal of \$30 million for FY90 and additional sums thereafter. The legislation has 45 bi-partisan Senate co-sponsors and was unanimously endorsed by the Senate Committee on Labor and Human Resources. It is our hope that it will be considered by the full Senate following the recess. In the meantime, a Kennedy amendment to the Appropriations bill secured \$30 million for 1990, so that thousands of low-income people with AIDS will receive life prolonging drugs.

3). As Chair of the Labor Committee I have exercised oversight of the Food and Drug Administration (FDA) and National Institutes of Health (NIH) in the development of AIDS drugs. We have worked to secure much needed manpower for these agencies and to reduce needless red tape. Our goal is to expedite safe procedures -- the most recent example is the "parallel track" proposal being worked on by the advocacy community, the Public Health Service, and the Congress.

4). The community-based clinical trials program was authorized in the omnibus AIDS bill of 1989 and the first round of grants has just gone out. This program is designed to make experimental drug trials available to individuals who have not traditionally been able to participate in institutionally based programs.

5). The health care service provision of the AIDS bill is designed to begin to diversify health care options for people with AIDS. We know that many people with AIDS continue to receive inpatient hospital care because no alternatives are available. Home and community-based care is more cost-effective and humane. A Kennedy amendment to the Appropriations bill secured \$20 million in FY90 to develop such networks.

Proposed Initiatives: 2nd Session, 101st Congress (1990)

\* These initiatives are part of a bi-partisan effort to respond to the increasing health care needs of people with AIDS and HIV disease. They will build upon the health care services title of the Health Omnibus Program Extension Act of 1989. In addition, the AIDS care agenda for 1990 is a combination of initiatives to address the special needs of people with AIDS and make necessary changes in the health care system to deal with the dual epidemics of AIDS and drugs --- see attached summary.

PROPOSED AIDS CARE INITIATIVES (1990)

1. Impact Aid/Emergency Relief Fund: Direct emergency relief grants to metropolitan statistical areas (MSAs) with greater than 2000 cases of AIDS or an incidence rate of AIDS greater than 20/100,000 as of January 1, 1990. These federal funds will be available for award within 90 days of enactment in order to provide emergency relief to approximately 20 MSAs which currently have 60% of all U.S. AIDS cases. The AIDS health emergency is overwhelming the infrastructure for health and support services in these areas.

Grants will be made to local political divisions. Funds provided must supplement and not supplant existing city, county, or state resources currently available for health and human services. These emergency relief funds may be used for the following purposes.

(1) direct compensation to hospitals, nursing homes and sub-acute care facilities currently providing a disproportionate share of services to low-income individuals with HIV disease;

(2) development or rehabilitation of sub-acute and long term care facilities, and congregate care residences; funds used for new construction must be matched by the state, county or local political division.

2. Networks and Consortia for Continuity of Care: Grants to state health departments and local consortia of health/social service providers (public and not-for-profit agencies) and community based organizations for the planning, development, and/or delivery of comprehensive outpatient and support services for individuals with HIV disease, including child & family services.

In 1989, the nation will spend \$2.6 billion on AIDS health care services. By 1992, the amount will rise to \$8.5 billion -- 1.5% of the nation's total health expenditures. The lack of urgently needed alternative care systems and gaps in existing reimbursement mechanisms are causing unnecessary overutilization of acute health care services. As a result, entire inpatient care systems, particularly in the inner city, are being endangered.

Essential Health Services should include case management, outpatient medical and dental care, diagnostics, mental health, developmental and rehabilitation services, home health and hospice care. Essential Support Services should include transportation, attendant care, home health aide, day/respite care, child welfare and family services, housing and benefits advocacy.

Funds should be allocated based upon an applicant's ability to demonstrate local or regional needs for such services and the applicant's ability to develop an effective and cost-efficient response to unmet needs.

3. Health and Human Services Manpower Expansion: Both urban and rural health care facilities are experiencing severe difficulties in attracting skilled health personnel. Individuals with HIV disease and drug users require an intensive level of care. In addition, as both epidemics expand, resources generated through volunteer groups are insufficient to cover the increasing gaps in services. Despite the claims made by the Reagan Administration that the surplus of physicians would ultimately send doctors into rural and urban underserved areas, this redistribution has not materialized.

Through a revitalization of the National Health Services Corps, which involves federal loan repayment program for medical education, more health care professionals will be available for assignment in underserved inner cities and rural areas. The Corps will be expanded to include nurses and social workers to assist in the delivery of care and case management for individuals with HIV disease and drug users. A redesignation of communities hardest hit by the twin epidemics of AIDS and drugs as health manpower shortage areas will permit the reinforcement of existing care programs.

Through VISTA, new incentives will be available to encourage volunteers to provide assistance to programs serving people with HIV disease and drug users. These volunteers can deliver critical services such as meals-on-wheels, "buddy" programs, non-medical transportation, and shopping, which are not reimbursable through public and private insurance programs. When effectively organized, such supplemental services enhance independent living and reduce the need for institutionalization.

4. Health Services for the Homeless: Services essential to the relocation of homeless individuals with chronic illnesses into permanent residences will be provided, including case management, drug treatment, mental health counseling, and maintenance-of-residence health and home attendant services.

Homeless people with HIV disease, as well as those at high risk for homelessness, confront special challenges in finding and maintaining residences. In many urban areas, hospitals are reluctant to discharge such patients because of the absence of residential options in the community. Independent living is not only more humane -- it is more cost-effective.

5. Insurance Assistance Program: Direct grants to states to assist individuals with chronic disabilities to maintain private health insurance benefits for which they are eligible under the recently extended COBRA program. Individuals who give up their job because of chronic disability may now continue their employment-based insurance for 29 months following termination. This proposed program will fund premium payments to maintain private health insurance and assure continuity of essential services at a lower cost.

We again thank all of you for coming here now, and we will recess our hearing. Thank you very much.

[Whereupon, at 4:10 p.m., the committee was adjourned, subject to the call of the Chair.]





## AMERICAN HEALTH CARE CRISIS: THE ELDERLY AND THE UNINSURED

---

TUESDAY, DECEMBER 12, 1989

U.S. SENATE  
COMMITTEE ON LABOR AND HUMAN RESOURCES  
*Los Angeles, CA.*

The committee met, pursuant to notice, at 11 a.m., at Royalwood Care Center, 22520 Maple Avenue, Los Angeles, CA, Senator Edward M. Kennedy (chairman of the committee) presiding.

Present: Senator Kennedy.

### OPENING STATEMENT OF SENATOR KENNEDY

The CHAIRMAN. Good morning.

I first want to thank Marilyn Granger and all of the Staff here at Royalwood Care Center for their hospitality and generosity in hosting this hearing. We are seeking to develop a record that will be extremely valuable to us in the U.S. Senate, particularly to our Committee on Labor and Human Resources that has the responsibility in developing health care policy.

And I want to thank all of you that are joined with us in our audience today for attending our meeting. We are grateful for your interest, and for your attendance here.

Indeed I am grateful to all of you for the very splendid plaque which I will take back with me, and this very nice welcoming card here.

I spoke with my mother last night—my mother will be 100 years old next July—and she said you make sure you say hello to all those nice young people up there in Royalwood Care Center. So if any of you are up in Massachusetts next July 22, you come by to a 100th birthday. I am sure you will be very, very welcome.

Health care should be a basic right for all—not just an expensive privilege for the few—my family has been fortunate in being able to obtain the best in health care, and it ought to be available to every family. But today we face a crisis in the health care system that threatens the well being of every American family and communities around the nation.

Health care is the fastest growing, failing business in America. And the challenge is more serious then at any time since the enactment of Medicare in 1965, and no one is immune, young or old, rich or poor, city or farm, insured or uninsured.

Los Angeles is the second stop on a nationwide tour that I am taking on behalf of the Senate Committee on Labor and Human Resources, to explore this crisis. Everywhere I go I find that the

challenge we face involves four central problems. Each one of them is serious, and together they constitute a health care crisis of unprecedented dimensions.

There are too many uninsured and under-insured Americans. Long-term care is not accessible for all our senior citizens and the disabled. Health care costs are escalating out of control, and essential health care facilities in every part of the country are over-burdened to the point of collapse.

In California, especially here in Los Angeles County, the situation is even worse than it is in other parts of the country. More than five million Californians have no health insurance at all. Here in Los Angeles one out of every three children has no health insurance coverage. A larger percentage of citizens are uninsured in Los Angeles County than any other large metropolitan area in the country.

One of the most troubling aspects of the current crisis is the devastating impact on children. Every child in America deserves a healthy start in life. But too many are denied this basic birthright here in Los Angeles and all across the country.

One in every five children in America today—12 million children in all—have no health insurance coverage. And two out of three pregnant women who are uninsured, do not get the low cost effective prenatal care their babies need. Because of this neglect, too many infants do not even survive the first year of life. America ranks a shameful 19th behind 18 other nations in infant mortality. The infant mortality rate for Black infants in Los Angeles is considerably higher than the rate for Black infants in the United States as a whole. Forty percent of children do not complete the basic childhood vaccinations that are the first line of defense against serious disease. A quarter of all children have no physicians. The only family doctor they know is the hospital emergency room.

Senior citizens face a crisis too. They have worked hard all their lives to earn a secure retirement, but their golden years are threatened by the high cost of long-term care. Three million severely disabled elderly Americans need home care or nursing home care today. Forty to 50 percent of all senior citizens alive today will need nursing home care at some point in the future. Few can afford that care—even fewer have insurance protection.

Long-term care is not just a problem for the elderly. Few families are prepared either financially or emotionally to take full responsibility for meeting the challenges of providing long-term care for parents who need it; these families deserve our help.

When you compound the immense number of uninsured citizens with the soaring costs of health care, it is no wonder that the critical health care facilities are collapsing or cutting back.

Ten private emergency trauma rooms in Los Angeles qualify as trauma centers, and have closed their doors because they can no longer afford to care for the most seriously injured accident victims.

Every person in this room who might be involved in a freeway accident, is at a greater risk of death as a result. Even 3 years ago California hospitals were spending more than a billion dollars a year to care for those who cannot pay. Today care for the stricken

infants of drug dependent mothers alone, may cost that much. Realistic answers are available to stop the senseless slide and reform our health care system. The question is whether we have the political will to do so now when reasonable remedies can make the difference, or whether we will wait until the current crisis becomes catastrophic and more drastic surgery is required.

In my view we should take four major steps as soon as possible. First, we should require businesses to provide private job-based insurance to all their employees; second, we need to provide a public insurance program analogous to Medicaid for those who cannot get health insurance through a job. Third, senior citizens and the disabled deserve the same affordable protection against the cost of long-term care that Medicare was intended to provide against the cost of doctor and hospital care. And finally we need to take positive action to bring health care costs under control.

There are some who say that we cannot afford these steps to protect all our people; I say that we cannot afford to ignore this crisis.

And I look forward to the wealth of personal experience and knowledge that our witnesses today can bring to us.

These charts here, outline very briefly the nature of the crisis. This chart demonstrates the 15 million Americans who are either denied or do not seek care because of the cost. These charts indicate what happens to many of those in nursing homes, and the burden that is placed upon individuals and families trying to afford long-term care. And the last chart illustrates the strategy for treating the American Health Care Crisis.

We look forward to hearing from our witnesses here this morning, and we will ask Jim Krause if he would be kind enough to give us his particular story.

Jim, we are delighted to have you here.

I want to say at an outset to all of our witnesses, we are very mindful that talking about our health care needs, occasionally represents a real intrusion into our privacy. I think all of us like to protect that particular aspect of our lives, so I know that for our witnesses this morning, it will not be an easy task to share with us, share with others, their story. But I think with the stories that we will hear today, here at Royalwood, are stories we could hear in any community of America; and it's typical. And I think it's important that we build this record so that we can go back and talk to our colleagues, we can point to what we heard here today. I thank all of our witnesses for sharing their experience with us.

Jim, we would be glad to hear from you.

#### STATEMENT OF JIM KRAUSE, PRINTER, SAN DIMAS, CA

Mr. KRAUSE. Thank you, Senator and staff for having me here. I will get right to it.

Some time in late 1986—

The CHAIRMAN. Why don't you just tell us, Jim, how old you are, and where you live, if you would.

Mr. KRAUSE. All right. I live in Glendora—or San Dimas—and have a small print shop in Glendora. I am 61½ years old. I think the rest of this is probably better to—

The CHAIRMAN. Good. Fine.



Mr. KRAUSE. OK?

The CHAIRMAN. Great.

Mr. KRAUSE. You are right, you do get into the private parts.

Some time in late 1986, my medical insurance company which I had been with for about 4 years, became difficult to deal with as far as paying claims and so forth. A month or so later I found out why when I received notice that they had filed bankruptcy—this is one that was in California.

I started to work around—or looked around—for another company. I became shocked at what other companies were charging—which would then be a family plan. So I kept looking around trying to find the best deal so to speak.

A little time went by, and then about this time—and this will seem kind of silly, so bear with me for just a moment—I was working one day in about a 100 degree heat with little or no humidity—what we call a “Santa Ana” out here—and on the way home I was almost dying from thirst so I stopped and bought a huge cola called “A Big Slurp” or whatever it is, “A Big Gulp”—it’s about 1½ quarts of cola. I had another, and when I got home and shortly after dinner, I suddenly became ill and drove to the emergency room at the hospital—I felt like I was going to blow up. Tests and an exam showed nothing wrong, nothing seriously wrong. The next day my doctor double-checked everything and told me don’t ever drink 3 quarts of cola at once on an exceptionally hot day on an empty stomach—that’s the funny part.

Then shortly after this, I did apply for insurance with a company, sent a check. Two or 3 weeks later the application and the check are returned because some computer somewhere had picked up this little gastritis thing in the hospital.

The insurance company said that they needed more information regarding this. We went back and forth for 2 or 3 weeks. I sent them a letter from the doctor, I tried to get a letter from the hospital, finally got that sent. The insurance company asked for more information. For some reason or other thought it was very, very serious. And I couldn’t believe it was happening. I tried two or three other companies with the same result.

Anyway, it’s now about March 1987 and on April 15 I suffered what is called a TIA—a transient ischemic attack—it’s a small—for the purpose of this meeting, I guess you would call it a tiny stroke.

So after two CAT Scans at \$650 apiece, x-rays and other exams, one night in ICU, the hospital bill came to \$3,300. We paid \$1,000 down and started making payments. But no one could find anything wrong.

My doctor suggested we take further tests—I asked how much, and he said about \$4,500 and I had to tell him “No”.

It is important—I think you should know, and I want you to know, that the doctor and others now believe that further tests would have shown a possible future heart attack, or other problems, and we could have taken some very definite preventative action, but I couldn’t afford to have these tests or examinations—something that is called preventative medicine, I guess.

However, now, I found out that I am uninsurable for anything relating to cardiovascular, pulmonary, the digestive tract which doesn’t leave much.

Through the balance of 1987, I tried several insurance companies, several schemes, that I find out that I am really locked out as far as insurance goes.

Several people in the small center where I have my print shop, we tried to get together and create an association or something, any kind of excuse to get a group insurance going—they all are without insurance also by the way—but no company was interested.

In January of 1988, one year and 11 months ago, I had a massive heart attack. It happened at 6:30 in the morning. We got in the car and drove two blocks to the hospital. I stumbled into the emergency room and laid myself on the table and passed out—I didn't have time to fill out papers or argue about insurance, so we got by that hurdle.

I was occasionally conscious and then 6 days later, I had a pacemaker in my chest—it is still there—and was on my way home. I also had a bill in my pocket for \$32,000.

I am thankful for those doctors and that hospital and their skills. I really am. I am not bitter about that. But someone made a mistake, and a week later I am back in the hospital with severe phlebitis in the right leg. Another week went by and the bill is now up to about \$42,000 and growing. I got bills from people I didn't even know were in the city, let alone in the hospital, but I assume they were there.

We paid about \$4,500 down, and some payments; our savings now, whatever they were, are gone. And by the middle of 1988, or in the Fall of 1988, the hospitals and doctors and the bill collectors and some of you probably know what that's like, were becoming very nasty regarding the bills. We consulted with lawyers and others and realized that it would take, if we paid \$500 per month, it would take 7 years to pay this off—not counting any interest.

We filed bankruptcy in November of 1988 and it was final in March of 1989. Since then I have tried various ways to get insurance. The usual lying and cheating or stealing or whatever you want to call it, to get in there—into a group, that is—and it's very difficult. The doors are closed all over. I even tried to sell insurance for an insurance company—medical insurance—but the company insisted on insuring its agents, and I was uninsurable, so I couldn't be hired—that's the way it is.

At the present time I can only work about 6 hours per day; my daughter opens the shop; I finish the day when she leaves; she also has another job. My wife works full time—many times 6 days a week. Her employer promised medical insurance when she started, but now says that's not going to be available ever, and to go find another job if insurance is so damned important—which we are going to do. We are trying to sell the shop and we are going to get on with our lives, and we are going to try to find some kind of group insurance or something to get into—but there is more.

My prescription drugs run about \$105 a month. I have a daily patch I put on—it's \$1.40 apiece. There are pacemaker checkups of \$45 every month or every other month—some of you who have them probably know what I am talking about, so on and so forth.

We are sitting now without insurance and if we, or one of us get sick again, I don't know what we will do. I don't have any answer,

so I don't have any suggestions either—but it is scary. That's about it.

The CHAIRMAN. Thank you, Mr. Krause, for sharing your experience with us. We are all glad that you appear well and fit, and that you have been able to get through these various medical emergencies. But I think your case points out one of the problems in our health care system, what is known as the "pre-condition" which effectively eliminates individuals from being able to buy insurance. My son Teddy had cancer when he was 12 years old, and thankfully he is well. He lost a limb to the cancer—his right leg—and he has a very full and wonderful life. He cannot buy insurance as an individual in the United States of America for the rest of his life because of this pre-condition. He has survived cancer, but for the rest of his life he is uninsurable because of a pre-condition, and you are in the exact same situation—uninsurable—virtually uninsurable. It did not take long for those insurance companies to find out about your episode of gastritis. They were looking for a way of knocking you out of any possibility of insurance.

I understand that before these series of occasions took place you were paying up to \$300 a month, were you, for your family, for insurance?

Mr. KRAUSE. Yes.

The CHAIRMAN. Three hundred dollars a month. You went looking for health insurance as an individual, entrepreneur, small business man, successful small business man. You wanted to be able to provide for yourself and your family, but were excluded because of these pre-conditions, in spite of the fact that you were prepared to pay the premiums. You had to go through the health care system and you are now bankrupt because of debts incurred for necessary medical care. I think perhaps the greatest tragedy of it all is not only the expenses, but the anxiety that you and your family, six children, continue to have. And to think that in our society, it is difficult to put a dollar and cents figure on that.

Everybody is always asking what is the bottom line, what are the dollar and cents? Well, I don't know how you measure that anxiety. The fact that you are not getting those tests which you know you should have. That is, I think, a tragedy—let me ask you, Mr. Krause, do you know others that have similar kinds of circumstances, similar kinds of problems of not being able to obtain insurance?

Mr. KRAUSE. Yes. There are several in the center where I work.

The CHAIRMAN. Do you think insurance ought to be a right for Americans; some form of coverage?

Mr. KRAUSE. Yes, of course it is. There should be.

The CHAIRMAN. There should be. Thank you.

OK. Carolyn Hanlon. We are glad to hear from you. I understand that you were there on a snowy day in 1961—in Washington, DC, at an inauguration. We are glad to—

Ms. HANLON. That was John.

The CHAIRMAN. John. Fine.

Ms. HANLON. My husband.

The CHAIRMAN. John, that's right

Ms. HANLON. John Hanlon was—

The CHAIRMAN. Good.



Ms. HANLON. I would like to have him sit by me.

The CHAIRMAN. Surely. He can come on up.

Come on up, John. We are glad to have you here. Come right up here.

Ms. HANLON. Is that OK?

The CHAIRMAN. Glad to have you, John.

**STATEMENT OF CAROLYN HANLON, ACCOMPANIED BY HER  
HUSBAND, JOHN ALBERT THOMAS HANLON**

Ms. HANLON. My husband, John Albert Thomas Hanlon, he was at your brother's inauguration, sir.

The CHAIRMAN. Fine. I think I remember him out in that crowd up there. I wouldn't forget that face there. I bet he has a little Irish blood in him too. Nothing wrong with that.

Ms. HANLON. John is 52 years old, and I am 49.

John worked for a defense contractor in Redondo Beach up until 2 years ago when he was sent home with terribly high blood pressure as a result of strokes, and he hasn't worked since August 6 of 1987.

He is brain damaged as a result of those strokes, and I entered into the world of care giving.

Part of that stress that isn't measured in dollars and cents that you mentioned, Senator, is measured in the loss of normal every day activity, such as my being able to accept a promotion to an executive position I couldn't handle anymore. I had to forego that promotion because of the stress.

I am no longer able to work. I work part-time. We sold the farm and a car, and at this moment, even after having spent \$37,000 for hospital bills, and \$12,000 out of our pocket, even today we are \$18,000 in debt.

John was a very good provider to our family. I don't know what to tell you, sir, except that the factor that some of these families are devastated financially by their loved ones' illness, we need help.

The CHAIRMAN. Let me ask—as I understand, Carolyn, you also care for your 71-year-old mother?

Ms. HANLON. Yes, sir. At home.

The CHAIRMAN. At home.

Ms. HANLON. She helps pay the rent.

The CHAIRMAN. That's good.

It took both of you 5 years to save the \$20,000 down payment for the home that you bought in July 1987, is that right?

Ms. HANLON. Yes.

The CHAIRMAN. And then that first stroke occurred in August of 1987; the hospital bill was \$37,000—

Ms. HANLON. The first stroke.

The CHAIRMAN [continuing]. And that was picked up by the defense contractor—part of it—but you still had some serious out-of-pocket expenses. Isn't that correct?

Ms. HANLON. Yes.

The CHAIRMAN. The drugs, the doctors' bill and the home care as well?



Ms. HANLON. That's true. One of the other reasons why I had to quit my full-time employment was because it was costing \$800 a month to have someone come in and take care of John. I couldn't afford \$800 a month, so I came home to take care of him myself. And then he had more strokes and went into a board-and-care place last December, and that was \$1,000 a month. And from there it was this past March that he had the \$37,000 hospital bill.

The CHAIRMAN. What resources are available for families in your situation; either voluntary organizations or government resources; have you found any care giver groups to be helpful?

Ms. HANLON. That's the first thing I did, because I was mentally ill. Those of us who—his loved ones—suffered immensely. In care givers' groups we have come to call that immensely contagious disease because we catch it too.

It is just an ongoing process, and if one isn't in a care giving group, you have absolutely no emotional support. The care givers groups, the Los Angeles Resource Center which is no longer in existence, was the best thing that ever happened to me, because they referred me to all the different organizations that helped me personally cope with the tragedy that was going on in my life. And a lot of it is just word of mouth. There are so many people out there who have the answers for you, but you don't know what questions to ask.

The CHAIRMAN. As I understand you would like to return to school and become a court reporter. Is that right?

Ms. HANLON. Yes, sir. It is one of my dreams.

The CHAIRMAN. Would that help if you were a court reporter, increase your income?

Ms. HANLON. Certainly, because I am only working 4 hours a day now. I only bring home about \$100 a week, and that is just because of my own stress that I have to cope with. And I am planning on going back to school next February. I will have to go nights. And hopefully I can establish another career.

My income—any income that I have right now—is the result of John being employed for all those years. Should something happen to John, I certainly won't have any more income, and I have to be ready to support myself.

The CHAIRMAN. What has been the most difficult part of caring for John?

Ms. HANLON. Very personal and very abstract thing, but it is coping with the denial. It is going to be a marriage counselor because something is wrong with your marriage and you can't figure out what it is, and nobody suggests going and getting a physical. And then you find out that that is what is wrong with your marriage, your husband is brain damaged from strokes. And it was the loss of him. The loss of him in my daily life.

The CHAIRMAN. Well, Carolyn, you are a remarkable woman, and John is very fortunate to have you as his partner. I appreciate your willingness to share this with us, you've got a lot of courage and he has too. We're very grateful. I just want to give you all the assurances as well as to all of our witnesses, we are going to do everything we possibly can to try and bring this country to its senses and get a universal insurance program.

Ms. HANLON. I would like to address one of your solutions, sir, that is that employees be mandatorily insured, no matter how small the company they are working for. I worked for a large company for all those years and I had marvelous insurance, and now I am working part-time for a little company that only has three employees, and there is no insurance available. And so many people need medical insurance. And I thank you for that, sir.

The CHAIRMAN. We appreciate your mentioning that. Small businesses are facing some special challenges. In Hawaii, the small businesses provide health insurance, and they do well. So we can fashion a program and system to be able to do it.

But I appreciate your mentioning it, and thank you very much. We thank you.

John, it's good to have you up here. Appreciate it very much.

If Donna Van Tassel would come up, and Gene McCarthy—is Gene here?

Mr. McCARTHY. Yes, sir.

The CHAIRMAN. Gene, would you come up, please?

Ms. VAN TASSEL. Good morning.

The CHAIRMAN. We have a rather special occasion today because Donna's husband—it's his birthday today. Is that right?

Ms. VANTASSEL. Yes. He is 64 years old.

The CHAIRMAN. Well, we wish him a very happy birthday, don't we, everyone, we wish him a very, very happy birthday. [Applause].

OK, Donna, if you would be good enough to tell us your story.

#### STATEMENT OF DONNA VAN TASSEL

Ms. VAN TASSEL. My name is Donna Van Tassel, and I am 54 years old, and as I said, my husband is 64.

My care giving days started in 1982 when my father died and I had to fly to Ohio. And when we arrived there, we found my mother very emotionally disturbed, and we was there 6 weeks and we finally realized that we couldn't leave her there, so we decided to bring her back to California to live with us.

In 1983, it really started because she had heart trouble. She was a diabetic, and she started having black outs and different things, and times of forgetfulness. So there were many trips to the doctor to see what was going on and at the end of 1983 she had to have surgery because she was a candidate for a massive stroke.

My husband and I began to realize that we needed help and so we asked my sister to move in to help me a little bit, and help with some of the finances because my mother didn't have any supplemental insurance, so we had to pick up what Medicare didn't pay. And her medicine was quite expensive, and so she decided she would move in.

But after the surgery, we got a lot of bills from the doctors because a lot of them didn't accept assignments which I didn't realize and know anything about because I wasn't into Medicare right then, but I learned fast.

In 1984, she began to have a lot of angina attacks and emergency room calls and this and that, ambulance trips and things like that to the hospital, and that meant we had to pay for our ambulance trips and things like that because we still couldn't afford the sup-

plement insurance. Later on we did try to get together and get that, and that was, you know, \$50 to \$60 a month for that, but we had to do something.

I saw that our utilities and things became higher because she was there every day. We had quite high utility bills, and I would try to burn our fireplace to kind of cut the bills down on the gas, because it was quite expensive.

Like I said, her medicine was very expensive, and I joined the AARP group to try to cut back on her medicine and everything, and that meant trips out to Long Beach to pick these things up.

In 1984 she had a couple stays in the hospital from the angina attack and a social worker approached me and let me know that I could apply for SSI because my mother's income from her Social Security was only \$331 a month. So I looked into this.

By this time we got the diagnosis from our doctor that she had Alzheimer's and it wasn't just being senile.

Like I say, by 1986, our lifestyle began to really change—financially and socially. At this time we faced another decision in our lives and everything. Developers had come in and started buying homes around us, so that meant they were building apartments and things up around our homes, and so we had to make a decision to try to maybe move so that we could have a quiet, decent life, because we knew apartments, we were going to have a lot of traffic and people.

So, my sister decided she would help us to see if we should buy another home, and we started this the first of the year, and by the time the escrow started to close and everything, my husband was laid off, so this meant a hardship and this meant, you know, I couldn't even go to work because I had my mother to look for to take care of 24 hours a day. So this gave us another big set back. Then the biggest thing that really got us is he was laid off, we knew our health insurance was gone.

So, he started looking around and by the time you are 61 years old, you don't find many jobs in the retail business or anything else. But he went out and he found different jobs, you know, in sales—he's a musician—and he played jazz, so he would go out and get jobs with the clubs and play to supplement our income. But still we had this fear of no hospitalization or no health insurance.

By 1987, I was really worn down to a frazzle, and I got in touch with the Alzheimer's Association to find out what I could do for help or support, or anything. So then they told me to get in touch with my social service to see if I could get some in-home help to come in and relieve me for a few hours. I did go and apply for that, but it was only 43–49 hours a month that they would give you help. And that's not too much help, but it was better than nothing, because when you are with someone that has Alzheimer's 24 hours a day, it is very stressful.

I did get some help from that and we got a lady to come in and give me a little help on my care giving. In the meantime, I was about ready for a nervous breakdown, and I got in touch with the Alzheimer's and they directed me to a support group, and I did this twice a month, we would get together and this helped a lot, because I learned a lot more about Alzheimer's. I learned a lot more



about what was going to come, and what I was going to have to face later on.

When I got my lady to help me and everything through the in-home service, they gave me no more hours to help my mother, but their pay scale is only \$3.75 an hour. And there is not too many people you can find to come in and help you for that. So my sister and I and my brother who lives out here, we decided we would go together and try to make it where it would be at least \$6.00 an hour and she said she would work for that, to give me about 4 or 5 hours a day, because my mother by the end of 1988, and the first of 1989, my mother couldn't do anything. She lost her speech, she couldn't feed herself, she couldn't go to the restroom by herself—everything was just really going down fast. And then in 1989 she had an attack where she stopped swallowing, and that's when I found out that I couldn't do any more and I had to put her in a nursing home which I faced the fact, and I did look around for nursing homes a year before, and I had my eye on one. And our doctor said he would go and make the visits to see her, and that's when I made my decision to put her into the nursing home which was devastating.

By the time—like I say, it was all this. We had a lot of financial expenses that was hitting us and like I say, our payment for our home was quite high and we had a life savings—our savings are depleted now. But my mother died October 6th and now I am trying to get my life back together. I am trying to go back into the work force so I can help my husband, and so I can get some hospitalization or some health insurance for us.

I just want to let you know I am thankful for my husband and my family, our doctor, and the Alzheimer's Support Group, because without that, I couldn't have made it for these many years.

The CHAIRMAN. Well, Donna, it is wonderful to mention the Alzheimer's Support Group, and we know the good work that they do, and it's a credit to them that they have been able to provide you with the kind of support that is so essential for you.

As I understand, your life savings have been vastly depleted, and this is even though Mrs. Moseley was covered by Medicare, and eventually Medicaid. Is that correct?

Ms. VAN TASSEL. My mother—Mrs. West.

The CHAIRMAN. Mrs. West. Excuse me.

And even though she had Medicare, all these other expenses really came out of your pocket and—

Ms. VAN TASSEL. Well, at the beginning we didn't have some of this; we had a lot of ambulance expenses which, you know, we paid for.

The CHAIRMAN. They are not covered, are they?

Ms. VAN TASSEL. No. And then I realized also that she didn't have anything to bury her, so my sister and I decided to get a burial insurance for her. We knew we wouldn't have the money to do this, so this was money every month that we had to take out. And we had to have a weekend off once in a while. To get somebody to come in was about \$75 to \$80 a day, and we would scrape together some money so that we could get a rest once a month—that was better than nothing. So that was an expense.



She had to have diabetic food and baby food and things, and like I said, we had \$30,000 in our savings and by me not being able to go to work and help, it depleted our savings.

The CHAIRMAN. Well, thank you very much, Donna. We admire you and we hear you and we will work, as I mentioned to other witnesses, to try and see if we can't address the situation which has given you such anxiety, and I am sure provided anxiety for the other members of the family.

Thank you very, very much.

Ms. VAN TASSEL. Thank you.

The CHAIRMAN. I believe Mr. Gates is here now, is that right?

We will now hear from Mr. Gates—if that's OK, if that's satisfactory?

Mr. MCCARTHY. That's fine.

The CHAIRMAN. You stay right there.

Thank you very much.

Mr. Gates is the director of health services, Los Angeles County. He has held this position for several years. His responsibilities include all the 6 hospitals and 48 health centers operated by Los Angeles County. They have an annual budget of \$1.6 billion, and provide 2.9 million outpatient visits per year. You have a very, very important responsibility, and we look forward to your testimony here today.

Earlier today, we had an opportunity to visit the Harbor UCLA Medical Center. We were enormously impressed by the challenges which are presented to it, but absolutely inspired by the quality of personnel that are there.

Mr. GATES. There are very excellent personnel there at that hospital.

I brought some written testimony which I will leave here; certainly I would not wish to read through.

The CHAIRMAN. We will make that a part of the record.

Thank you.

#### STATEMENT OF ROBERT GATES, DIRECTOR, HEALTH SERVICES, LOS ANGELES COUNTY, LOS ANGELES, CA

Mr. GATES. I thought I would talk about three or four major problems that are confronting Los Angeles County at the moment. One is something you may have heard about which is the collapse of our trauma system.

About 4 or 5 years ago when we put that program together we had 23 trauma centers that cover the county, and everybody could count on being within 20 minutes of the trauma center if there was some accident, or some other incident that they were involved in, that they could pretty much rely on being at a trauma center within that period of time. Now we are down to 13 trauma centers, including three county operated. So whereas before we had 20 private, three county, we now have 10 private and three county. One of the results of that is that there are several large areas of the county where there is no trauma coverage, where it would be too far, it would take the paramedics too long to get to a trauma center. So we see situations where people go not to a trauma center, but to a normal emergency room and the life saving capa-

bility simply are not present anymore. That includes the area around the large airport we've got down here.

Somewhat similar is a problem relating to emergency room coverage, mostly in the inner-city area.

The CHAIRMAN. Before we leave that, what do you expect from the trauma centers that continue to operate; do you expect that those will all remain open now for the next 3 or 4 years, or do you have some indication that there may be further reduction in the total number?

Mr. GATES. There could be further reduction. We are hoping that the passage of a cigarette initiative here in the State will provide enough money that we can at least keep in the system the ones that we have now. That produced—there's about—oh, as much as \$40 million between physician fees and hospital fees that might keep the system together.

The underlying problem of this and a couple other problems I'll mention, is essentially the lack of insurance coverage, where we have something like 25 percent—it may have been mentioned previously—something like 25 percent of the people in the State don't have health insurance, and that is particularly focused in the downtown area of Los Angeles. So we have a lot of problems facing the hospitals, the trauma centers, because they were collecting these poor patients into their systems and not being reimbursed, and when we get to the downtown emergency room, the same type of situation where there is too many patients who simply are unable to pay. That's the problem.

I might comment that at one point this was considered a problem of the poor people, and now it's affecting everybody in the county. Anybody who needs trauma care or in the central core area emergency care, runs a risk that it's not going to be available because of this lack of insurance coverage. In any event, I am hopeful that—

The CHAIRMAN. Would you explain that?

As I understand it, you've got reduced capacity and a shortage of beds, so you have increasing pressure put on these trauma centers. They have less capacity to be able to deal with trauma. Whether you have insurance or whether you are the wealthiest person in Los Angeles County with insurance or not, when you come on into that trauma center, you will have to wait.

Mr. GATES. Well, what happens is, as I mentioned, we have large areas of the county that simply don't have a trauma center within close range for anybody. And that's because of the added cost of maintaining trauma coverage, additional surgical coverage, additional anesthesia coverage, etc.

Hospitals find that it's simply not economical for them to continue, and that continuing on with their trauma service may threaten the entire existence of the hospital, and they can't allow that to happen. So they discontinue trauma services, and they're not available for anybody.

The CHAIRMAN. UCLA, and other medical schools, are picking up more and more of the costs of uncompensated care; are they going to be under similar kinds of pressures where people are going to have to make some decisions at the university level to say we're getting squeezed as well?

Mr. GATES. That's a potential future problem. That has not occurred to date. And one of the things we have seen is that the hospital serving the more affluent areas that have less of the uninsured population, tend to do better. So the facilities that are still in the private sector, are either one of two types. Either serving more affluent areas, or had teaching programs before. So a place like UCLA Medical Center, probably didn't have very much additional cost to become a designated trauma center. They already had the house staff there, etc.

I would certainly hate to see the day when UCLA would not be a trauma center.

Speaking a little bit more about this emergency room situation, in the downtown area we have been seeing situations where, again due to lack of coverage, hospitals have either closed or threatened to close their emergency rooms, or something more subtle, we see these days that hospitals simply become closed and divert ambulances away from their facility because it doesn't have capacity anymore. So we have seen an increasing situation where hospitals either have closed outright, or more threaten to do that, or in effect are closed and not available for services. We have been able to somewhat keep that system patched together, but it's a day-to-day situation, and I don't know whether you have heard from the fire services yet or not, but they have very severe problems when they pick up a patient and try to go to the nearest emergency room and it's closed.

We've had situations where half the hospitals or more in the downtown area aren't accepting patients. Usually that means they end up coming to county hospitals for care because we don't close normally. We have some special problems at some of our hospitals, but we try not to close our own facilities if it's at all avoidable.

Another situation that's facing us now, that's increasingly serious, has to do with obstetrical care. It's another form of emergency services, and we're seeing a greater and greater number of mothers coming into our system to give birth to the point where we're projecting something like 46,000 visits in our four hospitals that have OB services compared with a rated capacity of about 35,000. So we're running something like 30 percent more births in our system than our system is designed to accommodate, which is placing an intolerable stress on our staff.

Some of this relates to an increase in the birth, the total number of births in the county, but it also seems to relate even more to a shift from the private sector to the county. And again we see a complexity of related problems of patients who don't have coverage, physicians—maybe they're covered by the local Medicaid program—but physicians are so disgusted with all the procedures and all the hurdles for payment and the low payment rates, that they are not particularly interested in remaining in that program. And once again, the county ends up picking up the burden.

The CHAIRMAN. What is the level of reimbursement?

Mr. GATES. For hospitals, I've heard figures of 50-60 percent by the Medicaid program. For physicians they pay some fraction of the normal fees, probably 30-40 percent. Not a lot of incentive there. That's a current problem of great concern to us.



Finally, I'm sure you've heard something about AIDS maybe today. I'm not sure whether you heard that yet today or not, but we're extremely concerned about the impact of AIDS. We started out 5 or 6 years ago without really any expenditures for AIDS to speak of, and right now we're up to about \$60 million a year. That our hospital system has about 75 patients a day which is small by New York standards, but is an increasing number and is of great concern to us for the future.

The CHAIRMAN. Is that new patients a day?

Mr. GATES. That's the number of patients in our system every single day.

What we're seeing in general is that the private sector is unable to care for low income patients for threatening their entire financial survival, and the county system is overburdened, not funded because of various local, State and Federal policies, and anything that can be done to improve that situation, would be a great help to us. I think anything that would provide more universal availability of health insurance would help. Definitely. Anything that can be done specifically for so-called disproportionate share hospitals which are hospitals like ours that provide care to the large number of poor people, would be very much to the point, and in our particular case, further Federal support of the Immigration Reform Act which provides support for our system, is something that is of particular concern to us. We have a very large number of undocumented persons still in this county and newly legalized immigrants coming to us for care.

That's basically my presentation. I would be happy to answer any questions.

The CHAIRMAN. Thank you. It's very, very helpful.

What proportion of the patients who receive care in the county system do not have health insurance?

Mr. GATES. I would estimate with no form of health insurance, we're probably looking at 25 percent. There is probably another 50 percent that are covered by the Medi-cal program, Medicaid program. A very small percentage—probably 5, 6, or 7 percent of Medicare—the balance, insurance or payments come from private individuals, and a very large dependency on Federal, State and local tax sources.

The CHAIRMAN. Does the Department of Health Services have the capacity to care for all the uninsured patients in Los Angeles County?

Mr. GATES. No way. No. That's not a capability we have. In the past we have had to rely on the private sector, and the private sector has provided a great deal of charity care so-called, and something needs to be done to maintain that kind of capability.

The CHAIRMAN. The number of newborn deliveries in county hospitals and contract facilities has greatly increased over the last decade, and many of the mothers do not receive prenatal care.

Has this resulted in higher rates of infant mortality?

Mr. GATES. We have in the past been able to continue a downward trend, but with considerable difficulty. One of the things the county has done is try to expand access, and in the last couple of years we have added a great deal of capability so that a mother coming into our system now need wait only about 2 weeks for an



initial visit, whereas in the past we were looking at 6, 8, or 10 weeks in some cases.

We believe prenatal care is extremely important, and we made an investment in prenatal care. In fact ironically that may be one of the reasons we have so many mothers coming into our system now, is because we have made care available to them. But we believe that is a very sound investment.

The CHAIRMAN. Good.

OK. Thank you very much. I appreciate your willingness to give us an overview on it. We will make the statement part of the record.

Mr. GATES. Thank you.

The CHAIRMAN. We will hear from Captain Gene McCarthy who is the paramedic coordinator for the Los Angeles County Fire Department. He was a front line paramedic for 13 years, and has been the paramedic coordinator for 3½ years. He is also the past president of the California Rescue and Paramedic Care Association.

As I understand with you is Bob Hook who has been a front line paramedic driver for the past 2 or 3 years. Is that right?

Mr. McCARTHY. Yes.

The CHAIRMAN. As I understand, the Los Angeles County Fire Department has 360 working paramedics on duty. And a total of 1,000 working paramedics which includes all the cities in the county.

I look forward to hearing from you.

**STATEMENT OF GENE McCARTHY, PARAMEDIC COORDINATOR,  
LOS ANGELES COUNTY FIRE DEPARTMENT, LOS ANGELES, CA,  
ACCOMPANIED BY BOB HOOK, PARAMEDIC DRIVER**

Mr. McCARTHY. Thank you very much for having us here this morning.

The Los Angeles County Fire Department is but one agency out of 31 public agencies in Los Angeles County—a total of 41 provider agencies—providing advance life support here.

Within our department, as you have mentioned, we have 360 firefighter paramedics working on board squads responding throughout the community. And we cover the unincorporated areas of the county as well as the contract cities that contract for our services. We are a dual role personnel in that we are firefighters as well as paramedics.

We respond from fire stations. Our particular agency does not transport. We do provide both basic and advance life support.

We have a very large area to cover in Los Angeles County, and of the 4,000 plus square miles, the Los Angeles County Fire Department covers 2,186. And that goes all the way from the very high desert in the Palmdale-Lancaster area which is rapidly growing in population, and throughout the basin areas as well, and the mountainous areas.

We enter your homes and we see the pain and suffering that occurs each and every day, 365 days out of the year, 24 hours a day. And we see the anguish and the pain and the despair that happens in these families.

I listened with interest this morning of the people who testified so far, it is all true.

Our men and women in the L.A. County Fire Department, and the other provider agencies are very interested in providing care. They go to work every day and they put their 24-hour shift in, fully expecting to provide care and assessment and treatment with their physician brothers and sisters at the hospitals and nurses, but we find it increasingly difficult each and every day to do so.

I would like to kind of paraphrase one of my good friends in the L.A. City Fire Department—Chief Alan Cowan—who said that our EMS system is having a heart attack, and what it needs is an IV of money. Certainly system—to look at the system and its design and so on in the Department of Health Services working feverishly to—as Mr. Gates mentioned—putting together programs to forestall the eventual—what some people might say, the collapse. We need money; we need to address some very, very important issues on providing health care here in L.A. County. Especially when we are talking about trauma centers, hospital down, licensure and extended ETAs—estimated time of arrivals of paramedic squads—to the homes within the community.

As we find the population increasing and the people are poorer and sicker, and the drug abuse is more rampant, and more violence in the street, we find ourselves behind a rock. We need some help.

I brought along Bob Hook this morning, and he's got some stories—he's a front line paramedic today.

I spent some 13 years in the field, but I am in an administrative position now. I find myself helping to put the bandaids on this along with—and with committee work and so forth—and so if I may introduce you to firefighter paramedic Hook.

Mr. Hook. Thank you.

I think where I come into play here is I am the one that goes out and picks up, you know, some of the people they have talked about here today. And it's very, very frustrating not to have any place to take them.

We go to these people, we stabilize them, then we get on the radio and call our base hospital and find out—we tell them the hospital the closest to us—maybe 4 or 5 minutes away—and so our base hospital calls them and tells them we have somebody to take to them that's critically ill, they say, no, we can't take them, we're full.

They ask me to come up with another hospital to take them to. They cannot accept them. Now I'm taking this critically ill patient 15 minutes away. It's very frustrating in the field that we have no place to take these people. And that transport time, they need to be in the hospital, not in the back of an ambulance, especially at 5 o'clock in the evening, you know L.A. traffic, it's miserable. You can't get there. And trying to give care in the back of an ambulance in traffic, is very hard, and it's happening more and more.

We get a critically ill victim, we have no trauma center. I happen to be one of the people that work where there is no trauma center. And you get somebody that's very critically ill that needs that trauma center, we have to take them to a hospital that may only have one physician on duty, and a nurse. They're not going to get that proper care, but we have no trauma center to take them

to. And it's worse and worse. And we're finding ourselves as paramedics in the field, our priority after we stabilize the patient, is to get on that radio and find some place to take them, because so many times we have to wait 5 or 10 minutes until we call around just to find a hospital to take these people to.

It's very, very frustrating for us.

I can sit here—I have numerous cases—I don't want to take your time up with them—I can tell you cases—Would you like to hear a case?

The CHAIRMAN. Sure.

Mr. HOOK. OK. We had a 30-year-old—

The CHAIRMAN. First, why is it more difficult today than it was 3 years ago?

Mr. HOOK. Before I came here today, I prepared myself for this. I asked some paramedics that have been in the field for a while. Before you could get a critically ill person and head to a hospital because you know they would take them, or you had a trauma center that was only 5 minutes away, you knew was going to take them. Now, trauma centers are few and far in between. I have none within 20 minutes away. Hospitals now cannot take these patients. They are at the point now they are in a piggy-back system.

The CHAIRMAN. You said they cannot or will not?

Mr. HOOK. They are completely full. They have no room for these patients. So then you go to hospital No. 2, and if they can't take them, then you go back to hospital No. 1, and then if you call in again, then hospital two has—it's a piggy-back system—they are so overloaded. They cannot take these people. You know, before it wasn't like that; you could get a critically ill person and head toward a hospital and more than likely they would accept that patient. Now we can't do that because we don't know where we're going to go.

An example here is in fact the other day, I had a woman that was critically ill, in fact she was a gunshot victim. And the closest hospital was 4 minutes away. When my partner got on the radio, he called and they denied us. This lady had a blood pressure of 60 blackout patient which means she was in severe distress and was not doing real well. She needed immediate attention. I had no trauma center. The closest trauma center was probably 25 minutes away on a nice day. This was 5 o'clock in the evening. I couldn't have made it to that trauma center in 45 minutes with traffic.

I told them where my second hospital was; it was about 15 minutes away. They called that hospital. They denied me. They said we cannot take this patient. What am I to do in the field? I ended up going Code 3 for 17 minutes to a third hospital to take this patient. This patient passed on later that night.

That's one example. I can give you more.

Sitting out in the No. 1 lane of the freeway waiting to find a hospital to accept us. We don't know what direction to go. You know, we can't pick somebody up and then start heading to get them to the hospital immediately. There is no place to take them. And it's getting worse and worse. I have to start giving two and three hospital, you know, estimated time of arrivals because a lot of times the closest one is not—isn't going to accept this patient. And it's jeopardizing the patients. That's down to jeopardizing the patient. Plus



it's jeopardizing me going 15-20 minutes in an ambulance, taking me 20 minutes farther away from my area that I cover. Now it's another 20 minutes back, and our squads are so busy that now if you happen to get hurt in my area again, another squad is going to take 20 minutes to get into my area. Now you're jeopardizing those people that haven't even had any care yet. And they are not going to be able to get it because there is no time. There is nobody available. I have responded as long as 20-25 minutes to a location because that squad had to go 15-20 minutes to another hospital and we are flip-flopping. We see ourselves flip-flopping a lot. And it's becoming worse and worse.

Mr. McCARTHY. I would like to interject something here if I may, Senator.

The CHAIRMAN. Sure.

Mr. McCARTHY. We have 13 remaining trauma centers, and it's been said that's sufficient, really, to provide trauma care some would say. However, they're not located in the right places.

We have two trauma centers in Long Beach about a mile and a half to two miles apart. Of the original 23 located around the county, the 10 dropped out leaving very large pockets. The receiving hospitals that firefighter paramedic Hook mentioned, it isn't that they don't want to take the patients, it's that they're so busy with a population growth that occurred in the early 1980's, and with certainly the glut of uninsured patients, or the patients who have come here recently, that we have not provided a method of taking care of. Namely our new immigrants for example. We have not planned for that, and that's where we failed—our system.

The CHAIRMAN. Let me ask either one of you, are you aware of any suggestions that the paramedics should have to determine the health insurance status of the patient prior to transport to a trauma center?

Mr. Hook. Sir, I can relate this to another run where I had a gentleman who was hit by a vehicle, and I get to the hospital and the first question was, does he have a job. I said I was unable to ask him that; he was unconscious at the time. I mean that's hard for us to do that. We can't do that in the field. My concern is taking care of the patient, and it gets very frustrating with that, but we have no way in the field—and a lot of times we have—we are working on somebody and they are crying because they know the health costs and everything else is going on while we're working on this patient, and our only concern is the care of that patient. I don't care if he doesn't work, where he works or anything like that. And that's not my concern at that level. Now, when they get to the hospital, that's a different—they can handle that.

The CHAIRMAN. But do you ever have a sense that you are being turned off because the patient doesn't have insurance?

Mr. McCARTHY. About a month ago, two months ago, I believe, the Emergency Medical Service Commission, that question came up, and they categorically turned it down, and I was proud of it. That's been brought up around the country—Houston, I believe, the fire department—was asked to do that, and they turned them down—thank goodness. That's not our job.

The CHAIRMAN. That's right.

Mr. McCARTHY. It's not our job to determine insurance status.



The CHAIRMAN. But were you being asked to do that by the hospital association?

Mr. McCARTHY. No, we have not.

The CHAIRMAN. The increase in violence from drugs and gangs—has that increased the need for trauma care?

Mr. HOOK. I can say that. Yes. I actually went on seven gang related—I guess you want to call them murders, homicide—I don't know the proper term, in one week in my area. I had no trauma center—they were all gunshot or stabbing victims. I had no place to take these patients because I'm in a nondesignated trauma center. You know, I'm not to say that they would have survived if I would have had a trauma center to take them to, I'll guarantee you they would have had a better chance.

You've got to see a trauma center work with the critical—it's amazing. And you take these patients to the small hospitals, they are not going to get the care. And our gunshot runs and our stabblings have gone way up. And it is a lot of gang related. I can see that in the area I work in; it is very highly populated with gang members, and it is on the increase. You can tell with the drugs, you know, if the drugs are on the increase, if there is a new batch in that week, you are going to have some activity, and sometimes it goes rampant—on a weekend you will have 5 shootings in one weekend. It is increasing.

The CHAIRMAN. Thank you, very, very much. Good to have you. You are very, very helpful.

For our next witness, we have one last witness, Dr. Sokolov, who is vice president and medical director for the Southern California Edison Company. Prior to assuming this position 3 years ago he was an independent consultant on health benefits to Fortune 500.

We are very glad to welcome you here.

#### STATEMENT OF JACQUE SOKOLOV, VICE PRESIDENT AND MEDICAL DIRECTOR, SOUTHERN CALIFORNIA EDISON COMPANY

Dr. SOKOLOV. Thank you very much, Senator Kennedy.

I have provided testimony which is very similar to the Pepper Commission testimony that we were fortunate enough to give earlier this month.

The CHAIRMAN. Yes. I appreciate it very much.

Dr. SOKOLOV. And with your permission, I would like to just summarize a little bit the unique components.

First of all, Southern California Edison as many of you know, is a large electric utility here in the State of California. We are the second largest electric utility in the United States. But most importantly from our perspective, we have been extensively involved in the health care of our 54,000 employees, retirees and their families for almost 86 years.

This has taken the perspective of actually getting into the delivery of health care in no small way. We have clinics that handle over 100,000 patient visits annually. We have one of the largest corporate pharmacies in America filling 250,000 prescriptions, making us the third largest wholesale purchaser of drugs in the State of California. And then finally, approximately a year ago, we developed an extremely large preferred provider organization with

7,500 physicians and 170 hospitals for the Southern California Edison population.

This preferred provider organization even though it is exclusive to Edison, is one of the largest in the United States—actually being the seventh largest PPO by providers.

From that perspective, we were able to look at our health care costs that had been rising at close to 23 percent per year, and look specifically at health care cost containment provisions that provided an added degree of accountability within the corporation, as well as the individual participants. This caused our health care cost along with the other provisions of our plans, to drop from rising at 23 percent per year to rising less than 5 percent this year from 1988 to 1989.

We anticipated that these provisions would not only provide the accountability issues that were very important, but allow us to establish quality standards and evaluate issues that for the most part were very important from a corporate, as well as beneficiary perspective.

The other side of this coin in terms of looking at health care delivery, does not only include the reactive type of health care, but what type of an investment we were going to make in our people in terms of preventive health.

One of the areas that we felt was somewhat unusual and somewhat innovative, was specifically the good health rebate preventive health accounts. We have actually tied the price of our health care premiums to five modifiable risk factors that we test for each year. Those individuals who do not have one of these five modifiable risk factors, or agree to participate in a company sponsored program to lower that risk factor, actually receive \$120 off of their health care premium. For those areas that are not specifically covered in the health care plan, such as obesity or smoking, we provide up to \$100 in credits to give that individual a push in the right direction, and while participating in this program, they then qualify for the good health rebate.

We don't really believe that is going to help us in the immediate term—quarter by quarter, year by year—but at some point in time, that investment in our people will come back to help us. The tenure of our population is in excess of 16 years; our turnover rate is less than 5 percent; and we feel that the people who come to work for Southern California Edison will be there for a long period of time and they are worth the investment.

The CHAIRMAN. What are the five risk factors?

Dr. SOKOLOV. We look at specifically smoking, obesity, cholesterol, high blood pressure and diabetes.

As I mentioned, the impact has been significant this year, dropping our health care expenditures to less than 5 percent of an increase from 1988 to 1989. Eighteen million dollars under our historical trend on about a \$100 million base. But again, this is just the beginning of what needs to be addressed.

From a retiree standpoint, we have 18 percent of our population as retirees. They account for 28 percent of our total health care costs, and the types and diversity of services for those retirees are only growing. We needed to look specifically not at just cost shifting, but actually doing things that were a little different. Our gen-

eration program where we actively get involved and case manage retirees in a way that is meaningful, so that they can access resources whether they be social resources, welfare resources or medical resources, in a way that are important.

We hired the first geriatric social worker in corporate America. Doing this it allows us to ascertain whether individuals are truly maximizing the resources they do have, and in so doing, provide a better level of benefit for our people than they otherwise might have.

In addition, we are entering into Phase I with the Health Care Financing Agency to look at a Medicare Insured Group—or MIG. This program is a program where Edison has specifically administered Medicare benefits for our Medicare eligible beneficiaries.

Again, this is all part of the managed care program that we have evolved over the past few years.

It is somewhat unusual, and really one of the reasons why it is a pleasure to be here today is the fact that Edison is just not interested in it's small universe of 54,000 people. We believe that from a business standpoint, large corporations need to take an active role in terms of their responsibility of some of the issues that have been discussed here today.

We believe that for the most part, we do need to have a universal access program. There is no if's, and's or but's about it. Our people are very fortunate. They all have health care. Everyone in our corporation has health care that is provided by Southern California Edison. There are obviously large groups of individuals that don't have that benefit.

We believe that there are four components in terms of looking at the access issue that are critical. We think that first, there should be an expansion of employment related health benefits. Second, inclusion of employee cost sharing and utilization control mechanisms once this access is provided. Third, establishment of a uniform provider payment level so that people know what the maximum amounts of dollars they will pay for goods or services are before they actually need them. And then, fourth, there has to be an adequate equitable financing mechanism so that when one looks at providing access, there actually is funding in place so that these programs are not there in an under-funded and don't meet the goals or objectives for which they were established.

Finally, in conclusion, we basically come to the perspective that we can't really dig a hole and ignore the problem any longer. It is an area that from a business standpoint we have to become involved with. From the social consciousness standpoint we have to understand truly what parameters exist. And it is our feeling that we strongly urge that your proposals incorporate these cost containment mechanisms and payment reform necessary to assure that universal access becomes physically sound, permanent reality in the United States.

The CHAIRMAN. Very good. It is very difficult to take issue with your testimony.

Let me ask, what kind of health insurance package do you provide. The benefit package we have been talking about in Congress and the Senate is rather a bare bones package. We would not pro-



vide many services that are currently covered in some employer's plans.

What is your package? I don't know whether you are familiar with the services that we have included in our mandated program.

Dr. SOKOLOV. Yes, I reviewed them before this morning. They are not entirely dissimilar to what we already do provide. When one looks at our indemnity plan program which is what we call health flex, it is a stand alone flexible health care benefit. We have extensive benefits that are the same for outpatient services, inpatient services, preventative health care that I have outlined extensively, obviously prenatal, well-baby care—all the things that you would anticipate seeing. But there is really a very important point that comes about with this benefit package, and I think it's one that we all need to consider.

Every single person of these 54,000 people who participate in the health flex plan, do spend a small amount of money for their health care. Edison covers 90 percent of the cost, but every single individual pays for 10 percent of these dollars that are expended. This creates a partnership between the company and the individual in terms of understanding that you cannot just blatantly go and use services when you truly don't need them. At the same time those services are very, very accessible and very ready for individuals who do need them at the time of need.

The CHAIRMAN. Let me ask you, have you done an evaluation as to whether cost sharing discourages patients from using services that might be necessary and essential?

Dr. SOKOLOV. It's a very interesting situation, because the culture of that is such that the company has largely provided health care for many years, and it is very much a situation where the individual employee believes that the company really has them as a primary interest, and it does. In terms of actually looking at utilization patterns for either numbers of dollars expended per incident or actual frequency of diagnoses, there is unequivocal evidence, and we are going through again the first year of full implementation, that the number and frequency and the cost per frequency of occurrence, is going down within the system. Now, keep in mind there was a large portion of this population that had free health care before this took place.

The CHAIRMAN. Do you think the various measurements and assessments of obesity, cholesterol, hypertension and diabetes, could be built into a national program?

Dr. SOKOLOV. Absolutely. I think issues of preventative health that specifically are under the control of individual's own discretion, have to be built into the premium structures as long as the individuals can afford it. It's obviously not viable if individuals cannot afford basic preventative services to penalize them for not doing modifiable risk factor types of programs. Having said that, for that population, they obviously should be incorporated into the appropriate issue so that they do not cause more such as prenatal and all the other issues.

The CHAIRMAN. How do you tell whether somebody stops smoking or not?

Dr. SOKOLOV. We actually do carbon monoxide testing, again, annually. We did almost 12,000 tests last year.



The CHAIRMAN. I will have to keep that in mind.

Dr. SOKOLOV. Let me tell you. These tests are quite extensive, Senator.

The CHAIRMAN. I notice that your costs are only going up at 5 percent. Is that correct?

Dr. SOKOLOV. That's correct.

The CHAIRMAN. Do you think you can hold that; are your projections about that level?

Mr. SOKOLOV. No, I don't believe so. I think again this year we are very fortunate. We are probably the largest corporation in America with over \$100 million in spending that will keep it under 5 percent. But realistically, we believe that again as we have mentioned here this morning, we don't swim in the stream alone, and we believe that our health care costs will be under 10 percent for next year, but there is no doubt that eventually the issue of access, cost shifting, all the things we have mentioned today, will impact us in a way that are truly not controllable from our perspective.

The CHAIRMAN. Do you attribute the low employee turnover in your company because you've got good health benefits?

Dr. SOKOLOV. It's part of a total employment package that makes people want to stay at Southern California Edison.

The CHAIRMAN. I think that is probably certainly true.

Are you able to leverage the expenditures you mentioned—\$100 million—in ways to get better bargains?

Dr. SOKOLOV. Absolutely. That was the primary reason we put together this preferred provider organization. Seventy-five hundred doctors and 70 hospitals are under contract to Southern California Edison, so that we know how much we will pay for health care goods and services before those health care goods and services are actually needed by our people. And in so doing, we have felt that of the total \$18 million in savings, about 38 percent of those savings are actually coming from economies and provider contracts—doctors, hospitals, etc.

The CHAIRMAN. Do you think that is applicable at a national level as well?

Dr. SOKOLOV. Absolutely. As long as it is applicable across the Nation, that will decrease variability. The other proviso is that when one looks specifically at fee schedules or limitations of payment, that those payment levels be realistic, not like Medicaid and not like some of the others that are just unequivocally too low.

The CHAIRMAN. Let me ask you, do you think that the Federal Government might similarly leverage. We purchase great quantities, certainly in terms of drugs and we have not been effective at leveraging these dollars. The VA has not been effective in using economies of scale to try and leverage that, to try and provide some savings.

Do you really believe that can be—

Dr. SOKOLOV. Absolutely. In fact Edison has leveraged that size issue far beyond its real purchasing power. Even though \$100 million is a large amount of money in terms of the health care environment, it doesn't compare to the Federal Government or the VA.

Having said that, our pharmacy is probably the best example. We fill a quarter of a million prescriptions annually; the third largest wholesale purchaser of drugs in the State of California; 40 per-

cent below average wholesale price. We translate those savings to our people. We charge them a minor administrative fee and then they get the cost of the drugs.

The CHAIRMAN. I would like to put you in charge of our whole health care system—but I'm not in position to do it.

We want to thank you very much. We will be calling on you. We value your advice to the Pepper Commission. Southern California Edison deserves a great commendation. Really, it is corporate leadership at its best in terms of this issue. You have demonstrated what can be done, and obviously have stated that it should be done, and I think that is really enormously refreshing.

I just want to commend you and the corporation for what they do. And I think it adds enormous credibility in terms of their posture and positions on many different issues; someone that really cares about people.

We thank you very much.

Dr. SOKOLOV. Thank you, Senator.

The CHAIRMAN. We want to thank all of you very much, for your courtesy, and for your attention, and the committee stands in recess.

(Whereupon, at 12:30 p.m. the committee adjourned, subject to the call of the Chair.)



# HEALTH CARE CRISIS IN INDUSTRIAL AMERICA

---

WEDNESDAY, DECEMBER 13, 1989

U.S. SENATE  
COMMITTEE ON LABOR AND HUMAN RESOURCES  
*Maplewood, MO.*

The committee met, pursuant to notice, at 10 a.m., in the Maplewood Baptist Church, Maplewood, MO, Senator Edward M. Kennedy (chairman of the committee) presiding.

Present: Senator Kennedy.

## OPENING STATEMENT OF SENATOR KENNEDY

The CHAIRMAN. Good morning. The committee will be in order.

I want to first of all say what a real pleasure it is to be back here in St. Louis and to be here at the Maplewood Baptist Church. I am very appreciative to all those people who have been so helpful in making the arrangements for our hearing this morning and having an opportunity to bring into our Senate Labor and Human Resources Committee record, the stories that we're going to hear from hardworking American families in the heartland of this country.

And I wanted to say what a real pleasure it is to be with a distinguished congressman and someone who I've had the good opportunity to call a friend for many, many years. It's over 20 years since he's been in the Congress of the United States, the chairman of important committees that effect the health care of the people, not only of his constituency and the people of this State but of the country. Bill Clay is a very special individual and a very special congressman. The people of St. Louis are fortunate to have him and they keep sending him back to Congress. I consider it a real personal honor today to have a chance to visit with him and learn with him some of the real challenges of working families in this community.

And what we learned here is really replicated in communities all over this country. This is a continuation of our trip—the Labor and Human Resources Committee trip that will take us across the country. It started in Boston the earlier part of this week, and then to Bronx-Lebanon Hospital to look at some of the impact on a major urban hospital and what was happening in New York is being replicated all over the city.

We travelled yesterday out to Los Angeles and visited some of the county hospitals out there that are providing extremely important health care services for needy people, so many of them who lack insurance and see the burdens on community hospitals. In fact, 10 of the trauma centers, those are the centers that deal with



emergencies—whether they may be a heart attack, or violence, or accidents on the highway—are closing down because of the reductions in the coverage for health insurance.

And now, we've come really to the heartland of this country—the heartland of Industrial America to listen to working families who are really the backbone of this Nation to find out whether the health care system is working for them or working against them. And I think we'll hear from some of the witnesses that are here today about how hardworking men and women are facing challenges themselves, their loved ones, their family. And we will see how the system is working to their disadvantage in so many instances.

And then we'll continue down to Sparta, GA, to review what's happening out in Rural America.

So this has been enormously valuable and helpful to me who has had a longtime concern with the quality of health care; who's had a sister who is mentally retarded and knows the great attention that is necessary for a child or, in this case, an older sister that needs some very special help; who had a son who spent a good deal of time, close to 2 years, in chemotherapy and lost a limb to cancer. We were able to get the best in terms of health care as a member of the U.S. Senate and with my own resources. And I will, hopefully, enjoy the 100th birthday of my mother next July. [Applause.]

She has been sick for some years, but she enjoys her children, although those of us who are her children think that she likes the great-grandchildren even a little better than her children—[Laughter.]

The CHAIRMAN [continuing]. Particularly the three of them that are named Rose, after her. So we know what it has meant for her, as for my father who lived 7 years after a stroke. We've been able to provide what we would call home care—long-term care, and do it in a way that has provided dignity for her and the members of the family, and how meaningful it has been to all of us to see that she has been able to experience that kind of good care during her senior years. And yet, we find that millions of Americans are denied it. We find the extraordinary need for it. We have the growth of the uninsured in our country, the need for long-term care, the explosion and out of control costs of our health care system that is enormously wasteful in so many ways. In many parts of the country, we see the expanding substance abuse and AIDS which is weighing the system down. We really have a health care system in crisis, and we're looking forward to finding out today, what the impact is on working families.

[The prepared statement of Senator Kennedy follows:]

#### PREPARED STATEMENT OF SENATOR KENNEDY

The CHAIRMAN. I want to thank all of you for giving me such a warm welcome. The "Show Me" State is certainly showing me the warmth and generosity for which the people of Missouri are well-known—it is as obvious and as beautiful as the gateway arch that welcomes us to St. Louis.

Congressman Bill Clay and I are here to focus on the problems of the current health care system, which have reached crisis propor-

tions for all Americans. In the past 2 days, I have visited several cities to investigate the health care crisis in America as it affects children, the elderly and citizens without health insurance. We also have seen the devastation of drugs, AIDS and the collapse of the hospital system on the East and West coasts.

This morning, we will be discussing the burden on working men and women, millions of whom must face the pressures of raising a family and caring for loved ones without the protection of health insurance.

Twenty-three million workers and their families have no health insurance at all. Their lack of access to even rudimentary health care can scar them for life physically—and ruin them financially. Right here in St. Louis, there are more than 140,000 men, women and children who have no health insurance at all.

This broad lack of coverage is also putting such severe strains on the health care system that many hospitals are facing collapse.

Sixty million other Americans have insurance so inadequate that they could be wiped out by serious illness. The fear of changing jobs or losing jobs and losing health insurance too, becomes a nightmare that threatens countless working families across the country.

Working Americans are the strength of our country—they deserve better treatment from the country that depends on their labor.

Today, we will hear from people who have encountered the hardship of making ends meet without medical protection for themselves or their families.

The Hoffman family should be able to live comfortably on the two incomes of both working parents. Instead, the illness of a child has left them with staggering medical bills that they may never overcome.

Jason Berretta cannot climb trees or play football like other children because he was born with cerebral palsy and epilepsy. Insurance is unavailable for children like Jason—despite the fact that epilepsy can be controlled in 85 percent of the victims.

We will also hear testimony from the people on the front lines of the crisis. Edna Dell Weinell, director of a family care center in this area, is one of Missouri's leading advocates for the medical needs of working and poor families. Betty Jean Kerr, executive director of the People's Health Centers, runs two top-rated community health centers in the area—one of which we just visited across the street.

Workers here with no job-based insurance face a cruel choice between private coverage they cannot afford and gambling with their family's health and financial future. "Don't get sick in America," we tell them, "because we'll ruin you if you do."

From the perspective of hospitals and physician, the choice is equally difficult—turn uninsured patients away, provide charity care and pass on the costs to patients who can pay.

In my opinion, health care should be a basic right for all Americans, not just an expensive privilege for the few. No workers in America should be denied the fundamental right to health care because their employers won't provide it.

Finally, one of the most troubling aspects of the current crisis is the devastating impact on children. Every child in America de-

serves a healthy start in life. But too many don't get it because their parents can't afford it—and society won't provide it.

One in every 5 children in America today—12 million children in all—have no health insurance coverage.

Forty percent of poor children—more than 5 million children below the poverty line—have no coverage.

In light of these facts, in light of these human tragedies, the only thing that is unacceptable is to do nothing. I am honored to be here in Maplewood, and I look forward to this hearing as part of the effort that is needed to persuade Congress that it is time for reform.

I hope that Congressman Clay would say a word at the start of our hearing, and then we'll do what we've come out to do and that is to listen to our witnesses and not to us.

#### STATEMENT OF WILLIAM CLAY, A U.S. CONGRESSMAN FROM THE STATE OF MISSOURI

Congressman CLAY. Thank you, Senator, and, certainly, we want to thank you as a community for coming here to bring forth the kind of publicity we need to get this legislation passed.

This crowd is indicative of the appreciation that the people in St. Louis have for your concern for health issues, and also, we wish to thank you for what you have been doing nationally in spearheading this fight.

We all know that the No. 1 problem in this country is access to health care. We spend more money than any other country in the world on health care and we receive less in return than those other countries.

We're grateful that you have come here to conduct this hearing this morning. My committee has conducted a series of similar hearings in the past 6 months and we're in a position now where we're about ready to mark the bill up and report it out for passage. I think we've got substantial support on both sides of the aisle for your bill, Senator, from the Republicans and from the Democrats. So, hopefully, we will be able to pass a meaningful, universal, health coverage bill next year when we go back into session. Thank you.

The CHAIRMAN. Thank you very much. Your statement is enormously helpful.

Now we will proceed to our witnesses.

We have always recognized that it's extremely difficult to talk about one's health needs, and what one has been through with their family. I think that that's something that all of us understand. If we have sickness, or illness in our families, we'd rather keep that as a real private matter, and I think that's endemic in terms of our American character. So, it's really asking a lot of these families to be able to share their experiences with us as we are asking today. But, we want them to know how valuable that information is for our colleagues and we want them to know that that kind of experience is really being replicated in every community, every village, town, and city in this country. And so, we hope to be able to build the kind of a wave which will be irresistible in terms of providing health coverage programs for our citizens.



So, we'll move right to our first panel which are three families that have faced medical problems without adequate or any insurance. They represent the increasing difficulties facing working men and women across the country.

Brigett McDaniel, a young woman who was recently diagnosed with a disease of her immune system. She's caught in a dilemma of being unable to afford a private physician, but is ineligible for subsidized care.

Neal Baretta is the father of two children. His son has cerebral palsy and epilepsy. Because private insurance will not provide coverage, his son is severely restricted from normal childhood activities.

And, Edward and Paige Hoffman will testify about a tragic accident that happened to their son. Their testimony will focus on the impact of a family when this kind of tragedy strikes.

We're glad to have you all here with us this morning. And we'll start off with Brigett McDaniel.

Ms. McDaniel.

#### STATEMENTS OF BRIGETT McDANIEL, ST. LOUIS, MO; NEAL BARETTA, KANSAS CITY, MO; AND EDWARD AND PAIGE HOFFMAN, JENNINGS, MO

Ms. McDANIEL. Good morning, Senator. Approximately 2 years ago, I went to a county clinic and I was told that I had asthma which they treated me for, for approximately 4 months.

After which—after seeing that I wasn't getting any better, I sought a private physician who did a chest x-ray the same day in his office, and I was told that I had a shadow on my lung, and that that was possibly cancerous and that I needed to have a biopsy done.

At the same time I was told those—I was asked if I had insurance, and told that if I didn't have insurance, I would not be able to be treated for this by him. At the time, I stated that I was a graduate student, and I thought that I was covered by school insurance and that it should pay for his fee and any hospital fee that I should incur.

So at that point, he put me into a hospital and I was seen by a pulmonary specialist where they did a biopsy and they found that the tumor wasn't malignant. I was then sent back to the private physician and started on a cortico steroid to shrink the tumor.

At this point, I found out that the insurance that I thought that I had would only cover one-third of my bill leaving me with a \$6,000 balance to the hospital, as well as, \$1,000 balance to the private physician, and other accounts with the specialist that I was seeing.

It was at this point that I stopped seeing the private physician because his fee also was between \$250 to \$400 per visit and I couldn't afford it since the insurance only paid one-third of—per account or per accident, so it was no longer going to pay on this disease. So I stopped seeing him.

And he sent my account, as well as my hospital accounts, to a collection agency who began to call me, harass me, and threaten me, and I was told that—I offered to make arrangements to make



a payment of \$30 a month and I was told that that was not suitable, nor was it seen as a good faith effort.

I explained to them my financial situation and that I was a student and I intended to try to get this balance down.

I was told that I needed to make a minimum payment of \$150 to \$200 a month to get this paid off, and that I should have thought about all of this before receiving treatment.

So it was after this—I wasn't sure exactly where to go, so I simply discontinued taking my medication on my own. I didn't want to incur any other debts and I wasn't sure how I was going to pay these, so I simply stopped all treatment.

This led to me being taken to an emergency room where I was told that I needed to see a physician, that I shouldn't have stopped taking the medication, and I was referred to another clinic that would treat me based on my income.

So I started treatment there where I saw a pulmonary specialist and, based on my income, each visit was \$10 a month with a copayment of a dollar per prescription. This was great; I was finally getting medical treatment.

My problem now is that my husband has been employed—he's finally found a job fulltime and he's eligible for insurance within 3 months. And I cannot be covered by that insurance since this is a pre-existing disease, and I will have to go back to paying full coverage for any medical expenses from here on out because he is insured, and he does have a fulltime job, and it's based on your income.

So now I'm faced with another problem of exactly where I should go or what I should do because I know that not only do I have to pay these previous bills that I already had, but I have to come up with the money now to pay for any medical services that I continue to get.

The CHAIRMAN. Well, this is obviously a matter of incredible concern.

The issue of a pre-existing condition is something which, I think, has to be troubling all families who have a member of the family that has some kind of illness and sickness over which they have no control.

My son, Teddy, for example, who had cancer when he was 12 years old and has recovered, can never buy insurance in the United States of America for the rest of his life because of the same kind of pre-existing condition clause. Just can't buy it. You're out. It's something you've had absolutely no control over and you're out.

Students are faced with other problems. Most of those student programs that have insurance usually cover one instance per disease or illness, and don't cover future treatments. So you have exhausted your coverage after the first treatment.

You have a husband who's obtained work which has health insurance. You're excluded because of the pre-existing condition and you don't qualify for Medicaid.

You're denying yourself the kind of medical treatment which the doctors who you have talked to said is important to treat your condition. And yet, you and your husband are faced every single day

with the anxiety of working and coping with the various challenges of life and caught in this extraordinary gap.

It seems the only people that look like they're happy are those collection agencies which is one of the fastest growing industries in the country. That says a lot about us. The fact that collection agencies are thriving is part of the dilemma in terms of how our system is structured.

Congressman Clay and I have a belief that if you can work, want to work, are working, you ought to be covered. And if you can't work or you have a disability you shouldn't face the kind of anxiety which you're going through.

Bill, at any time you want to comment.

Congressman CLAY. I look forward to hearing the statements.

The CHAIRMAN. OK. We'll move right along, if we could, to Neal Baretta and his family. Mr. Baretta, would you like to tell us a little bit about your family. You're a father of two children, isn't that right?

Mr. BARETTA. Yes, sir. I have a son that's 11 years old now. Jason, at 3 months old, was diagnosed of having cerebral palsy and a seizure disorder which is commonly known as epilepsy.

At the time he was hospitalized, we had a major medical insurance through an auto plant in Kansas City which covered all of his illnesses. Due to the economy, I was laid off with that auto plant and the insurance ceased.

At the time, we did not know that Jason could not be insured, so we went out and we tried to find an insurance company that would cover my son for his disability, and they told us no way. We contacted probably 14 or 15 different insurance companies. They wouldn't even talk to us.

Then he was hospitalized with seizures again at about the age of 9 months, and we had no insurance. The bills were coming in—\$30,000 to \$40,000.

We didn't know who to turn to at the time, so we started asking around to find some help. Luckily, we were told to notify or ask help from Missouri Crippled Children's Fund which is a State agency and taxpayers foot the bill. You are limited to income. If you go over a certain income, they won't cover you.

So they went back and they paid up the back bills, and we felt like that our son was getting better, but he didn't. He proceeded to go back in and out of the hospital. The Missouri Crippled Children kept picking up the bill.

You have to realize that when I say Missouri Crippled Children picks up the bill, they only pick up the bill for his seizures and his CP and nothing else. So, if he goes out and he breaks a leg or he goes out and he falls and he's hospitalized, I'm without insurance. In turn, would financially devastate me because hospital costs now-a-days are so high, with my income, I couldn't afford it. I just couldn't afford it.

So Jason is 11 now, and he wants to do what 11-year-old boys would like to do—play baseball, play football, soccer, ride a skateboard. He can't because he doesn't have any insurance. How do you tell an 11-year-old boy that he can't do normal things? It's hard. We have a hard time telling him this, but his neurologists say Jason is normal. He has no—he has one problem. He's normal. He

has a slight problem; he has seizures. They're controllable by medication, but insurance companies don't realize that. They put something over your head like seizures or any other disability and you have leprosy. They won't insure you. They won't talk to you, but he's still normal. And, I feel like it's an unjust to us as parents; it's an unjust to Jason because he cannot get insurance for the rest of his life, and he deserves and people deserve that right. Thank you, Senator.

The CHAIRMAN. Now, I understand that both you and your wife, Debbie, work fulltime?

Mr. BARETTA. Yes, sir.

The CHAIRMAN. And neither job provides health insurance, is that right?

Mr. BARETTA. Yes, sir.

The CHAIRMAN. And, both of you are working fulltime, and you have purchased health insurance at a cost of \$250 per month.

Mr. BARETTA. Yes, sir.

The CHAIRMAN. But, that only covers you, your wife, and your daughter, is that right?

Mr. BARETTA. Yes, sir.

The CHAIRMAN. And that's an extremely, costly program.

Mr. BARETTA. Senator, excuse me. When we were living in St. Louis, I was employed as a laborer which had a major medical health insurance program. They wouldn't cover Jason. They exempted him. It's not only the private individual policies, it's also the group health care that refuse coverage.

The CHAIRMAN. As Congressman Clay pointed out, we are trying to deal with the coverage aspect.

I'm very hopeful that we're going to pass the American for Disabilities Act which will change attitudes towards those who are considered to be "disabled". In our society, we need to address the attitude and, more importantly with the discrimination against people with physical or mental impairment. They should certainly be a part of the mainstream of American life. We have passed the bill in the Senate and I'm confident that they will pass the bill in the House, as well.

We have a Congressman who is an epileptic in the U.S. Congress who has had an important and distinguished career. He speaks about this problem with great eloquence.

We still have attitudinal roadblocks in our society which are reflected in a variety of different ways. We're going to do whatever we can to eliminate these problems.

Congressman CLAY. Let me say, also, Senator, that the points you made are the ones that we intend to cover in the legislation that we pass out.

I think it's shameful for a country as rich as ours to permit these kinds of things to go on, and it's an indictment of the Government, of the Congress, and of the presidency of this Nation, that two people working fulltime don't have any health coverage and can't get it. I think as a minimum this government is obligated to make people—who employ other people—to give certain kinds of minimal protections and adequate insurance is one of the protections that ought to be in any bill that we pass. I will be attempting to put it into a bill that's going to come out of the House.



The CHAIRMAN. Very good. Thank you, Congressman.

Mr. Baretta, I know it's a difficult thing to discuss, but what does Jason say to you when you tell him he can't go out and play with his friends? What does that do to you emotionally? How does he sort of react to it?

Mr. BARETTA. It upsets him. He don't understand, but then, he knows he's limited of what he can't do and what he can do. But he forgets, and he comes back and he asks the same question. It just—it's hard to describe; you have to be there and see his face when he comes home. He came in the house last week and said, "I want to play basketball." And I said, you know, "Jason, you can't."

The CHAIRMAN. Is that Jason right over there? Do you want to stand up, Jason? We're glad to have you here. You look pretty fit to me. Are you a basketball player?

Jason BARETTA. Uh-huh. I'd love to play basketball.

The CHAIRMAN. Yes. I bet you'd be pretty good at it, too.

Do you have any heroes on the basketball teams?

Jason BARETTA. Magic Johnson.

The CHAIRMAN. Magic Johnson. [Laughter.]

Larry Byrd up there a little bit? [Laughter.]

OK. Jason, we appreciate your coming here. I think you have a sense of the anxiety and the love which your parents, clearly, have for you. We have a real responsibility, as the Congressman pointed out, trying to do something about it.

Do you want to introduce the rest of your family? Ms. McDaniel, is your husband here?

Ms. McDANIEL. No, he isn't.

The CHAIRMAN. Well, that's fine.

Mr. Baretta, do you want to introduce your family?

Mr. BARETTA. This is my wife, Debbie, the better half that supports—

The CHAIRMAN. Good.

Mr. BARETTA [continuing.] Jason better than I do.

The CHAIRMAN. Stand up, Debbie, and is there anyone else from your family?

Mr. BARETTA. And that's my daughter, Kristina, she's gone through the difficulties, also.

The CHAIRMAN. Very good. We're glad you're here. Thank you very much.

Mr. and Mrs. Hoffman, we'll be glad to hear from you.

Mrs. HOFFMAN. My name is Paige Hoffman and my husband's name is Ed. We have two children, Eddy, who is 7 years old, and Autumn Marie, who is 5 years old.

On July 29 of this year, our son Eddy was struck by lightning in our backyard. It was a near fatal accident, and we are told you have more of a chance of winning the lottery than you do getting struck by lightning. We were also told he was not likely to survive. He was burned a little over 50 percent of his body with second and third degree burns and, as a result, had to have a blood transfusion. He was kept stabilized by being put on a life support system and was listed as critical for 4 weeks.

Eddy was in the hospital for approximately 6 to 7 weeks, and it is estimated that his stay in the intensive care unit was approximately \$3,800 a day. Being treated mostly as a burn patient, some



special equipment had to be flown into the hospital. The financial counselors at the hospital estimated that his bill, alone, will be in excess of \$200,000. We have already paid \$10,000 to \$15,000 of private bills and doctors services that were not included in the hospital bill through a trust fund set up by our local police department.

My husband, Ed, and I were both employed at the time of the accident, however, neither employer gave us access to, or provided health insurance. Because Eddy was critical for nearly 30 days, my husband and I were unable to work at that time. Due to this and financial problems within the company, itself, my husband lost his job. My employer gave me an open leave of absence, but because of the severity of our son's health problems, I have been unable to return to work.

Currently, my husband is working part-time. We still have been unable to afford health insurance, but when, and if, we are able to afford it, it's doubtful that we'll be—ever be able to insure Eddy. In addition, if we were able to afford insurance, it would knock out Eddy's State-aid which is still pending.

In some ways, we have been fortunate in that our community had a trust fund set up at Boatman's Bank to help with Eddy's medical bills which I spoke of earlier. However, this has caused numerous problems with Eddy's Medicaid and Social Security benefits regarding his eligibility.

Eddy's prognosis has not been encouraging. Little is known about this type of lightening case because most of the people who have been hit this hard have not survived, but we are still hopeful. Therapy has helped dramatically in helping his recovery, however, it has been slow and gradual. We don't know how long he will need treatment or how long we will be able to continue the therapy due to his State-aid being unknown and directly related to his trust fund.

The CHAIRMAN. Mr. Hoffman were you employed fulltime at the time of the accident?

Mr. HOFFMAN. Yes, sir.

The CHAIRMAN. You didn't have any insurance?

Mr. HOFFMAN. I did not have insurance.

The CHAIRMAN. And then you lost your job due to the amount of time you spent in the hospital.

Mr. HOFFMAN. Right. We lived at the hospital for quite some time.

The CHAIRMAN. As I understand it, you worked for that company for 12 years.

Mr. HOFFMAN. Right. We used to have insurance, but it was lapsed 5 or 6 years ago, and we never gained it back again.

The CHAIRMAN. This is one of the trend lines that we are seeing. What's happening is that we are seeing increasing numbers of uninsured people in our country.

Are you currently able to work part-time?

Mr. HOFFMAN. Right. I'm finding jobs here and there.

The CHAIRMAN. Mrs. Hoffman used to work two jobs, as I understand it?

Mrs. HOFFMAN. That's correct.

The CHAIRMAN. Yes. Neither job provided health insurance and she had to quit both those jobs to care for your son at home, is that right?

[No audible response.]

The CHAIRMAN [continuing.] Let me ask you, what options for care were available to you? Why did you make the decision to care for your son at home?

Mrs. HOFFMAN. The only option that they left to us was either to pull the plug on his life support system and take our chances, or institutionalize him.

The CHAIRMAN. That's not much of a choice.

Mrs. HOFFMAN. We could see, you know, respond—him responding to our voices and different stimuli. Whereas, the doctors that didn't know him couldn't see these gradual things. And I didn't feel he would get the attention that he would need to come out of this in an institution where somebody didn't even know him. Eddy was always a quiet and shy child; he's not going to respond to somebody he doesn't know.

The CHAIRMAN. That's an incredible choice for any individual, let alone a parent.

Congressman CLAY. What kind of treatment is he getting now?

Mrs. HOFFMAN. Currently, he gets therapy 4 times a week, occupational and physical therapy. As far as medications and that kind of thing, the only medication he is on is for his high blood pressure. The center that controls his blood pressure was damaged from the electricity, and he needs that medication to keep it stable. And he has a nurse that comes by, through Visiting Nurses Association, once a week to regulate his blood pressure.

Congressman CLAY. How do you pay for the medication?

Mrs. HOFFMAN. Right now, United Way has been helping us a lot. They've picked up for the Visiting Nurses Association and the therapist.

Mr. HOFFMAN. And the St. Louis Variety Club has helped quite a bit, too.

Mrs. HOFFMAN. With his equipment—his wheelchair, and a wheelchair ramp, and bath chair, and that kind of thing.

The CHAIRMAN. I think all of us are filled with admiration for what the voluntary agencies, like the United Way do. They are absolutely superb. But they cannot possibly meet all the needs of the increasing number of people with medical problems. Do you ever get out for a while? Are you ever able to go to a movie?

Mrs. HOFFMAN. We got out today.

Mr. HOFFMAN. We're here.

The CHAIRMAN. Yes, this is real entertainment. [Laughter.]

Mr. HOFFMAN. We get out every now and then.

Mrs. HOFFMAN. Not often.

Mr. HOFFMAN. It's seldom.

Mrs. HOFFMAN. Usually when he gets home, I fly out the door, and when I get home, then he goes out the door.

Mr. HOFFMAN. If we get out, it's usually one or the other goes out.

The CHAIRMAN. Yes.

Mrs. HOFFMAN. Yes, we don't usually get out both at the same time. That's unusual.

The CHAIRMAN. When you were working, did you ever inquire of your employers if health insurance was available?

Mr. HOFFMAN. Well, after we were canceled 5 or 6 years ago, yes, I had persisted to ask him for several years if we could ever get insurance back, because we could not afford it ourselves.

The CHAIRMAN. Yes.

Mr. HOFFMAN. But it never came around.

Congressman CLAY. How many employees were working with you?

Mr. HOFFMAN. Well, my boss, at one time, had it underneath a group plan which there was probably six people underneath the plan—before it was canceled, and, after that, everybody lost their insurance and no one ever got it back.

The CHAIRMAN. You have a 5-year-old daughter?

Mrs. HOFFMAN. Yes.

The CHAIRMAN. How has your daughter reacted to the accident?

Mrs. HOFFMAN. She hasn't done real well. She's doing better now. Her—just about her only playmate was Eddy, you know, so she's kind of lost. She doesn't have a lot of—there's not a lot of young kids in our neighborhood that are her age that she can play with, and the ones that are her age go to school. And she's not in school yet, so she's home pretty much of the afternoon by herself—

The CHAIRMAN. Yes.

Mrs. HOFFMAN [continuing.] And, you know, with me taking care of Eddy, I have little time to—

The CHAIRMAN. That's right.

Mrs. HOFFMAN. Spend what time I would normally be spending with her.

The CHAIRMAN. Do you have any savings?

Mrs. HOFFMAN. We have a little.

The CHAIRMAN. Yes.

Mrs. HOFFMAN. My father passed away in the last 3 years, so I have some money left over from his insurance.

The CHAIRMAN. Does the fact that you face these bills affect your credit rating?

Mr. HOFFMAN. We don't know that because we haven't really—

Mrs. HOFFMAN. We haven't run into that yet.

Mr. HOFFMAN. We haven't gone to purchase anything where we would need a credit rating.

Mrs. HOFFMAN. Yes. [Laughter.]

The CHAIRMAN. How is he doing? Is he improving?

Mrs. HOFFMAN. He's gradually improving.

The CHAIRMAN. Yes.

Mrs. HOFFMAN. He will respond to your voice now. He laughs. He cries. He can't speak, but he does get a few words out. He can say "Mom", and "Dad", and "Don't", and "No", and "Stop", and "Ouch", and—

The CHAIRMAN. Ice cream?

Mrs. HOFFMAN. No.

The CHAIRMAN. He doesn't say that?

Mr. HOFFMAN. I'd like to hear him say that.



Mrs. HOFFMAN. Our biggest thrill was when he really laughed and started smiling, because the doctors told us that he would never be able to respond to us. And, of course, he isn't holding an intelligent conversation——

The CHAIRMAN. Right.

Mrs. HOFFMAN [continuing.] With us, but at least he's responding to the point——

The CHAIRMAN. Right.

Mrs. HOFFMAN. To where we know that he understands what we're saying.

Mr. HOFFMAN. We, at least, feel that he's getting better.

Mrs. HOFFMAN. Yes.

The CHAIRMAN. Well, it's a great tribute to both of you.

Congressman CLAY. Mr. Hoffman, your case points up the need for another piece of legislation that we're trying to pass and that's the Family and Medical Leave Act which would have required your employer to give you some leave in your situation.

Mr. HOFFMAN. Right.

Congressman CLAY. The bill would assure that you could get your job back at the end of that leave. So, there's a lot of legislation related to health care that we need to pass.

The CHAIRMAN. That's an excellent point.

As the Congressman pointed out, we're the only industrial society that doesn't provide paid-parental leave. Legislation that is pending in Congress would permit up to 13 weeks for a child that is ill, or sick, or for an adopted child. You would not get paid, it would just enable you to get your job back after the leave. The number of people that are losing their jobs, as Mr. Hoffman has, is absolutely astounding. I don't think any of us in this room would think that people get fired because they have a sick child at home and they've gone back to take care of him, but it's happening. And it shouldn't happen.

Mrs. HOFFMAN. I don't know too many people that could go to work knowing that any day or any minute that your child could be gone. I don't know of too many people that could go back to work with that weighing on their minds.

The CHAIRMAN. We agree that health insurance should be a right. In addition, no parent should have to make a choice between the job that they need and the child that they love.

Mr. HOFFMAN. Right.

The CHAIRMAN. And that ought to be something that we as a society ought to be able to accept as well. I mean it's not a radical concept. It's a humane, decent, compassionate one which we haven't embraced yet, but we shall.

Thank you. I want to thank all of the panelists for sharing your experiences. You all deserve enormous credit for your perseverance and caring for the people that you love. I think it presents, more eloquently than the Congressman or I could state in speeches, what the real needs are in our society. I thank all of you, Ms. McDaniel, Mr. Baretta, and the Hoffman family.

Mr. BARETTA. Thank you.

Mr. HOFFMAN. Thank you, Senator.

Ms. McDANIEL. Thank you.

The CHAIRMAN. Thank you very much.



Our next panel are two experts who are on the front lines of providing medical care to the uninsured.

Betty Jean Kerr is the director of the People's Health Centers, one of which we visited this morning. She'll discuss the problem facing the uninsured, the trends she sees, the difficulties in finding the necessary expert care for the uninsured.

Edna Dell Weinell is the director of the Family Care Center. She'll provide testimony from a statewide perspective of the uninsured problem based on her personal experience at the center which serves a large number of working people.

Now, Betty Jean.

**STATEMENTS OF BETTY JEAN KERR, EXECUTIVE DIRECTOR, PEOPLE'S HEALTH CENTER, INC., ST. LOUIS, MO; AND EDNA DELL WEINELL, EXECUTIVE DIRECTOR, FAMILY CARE CENTER OF CARONDELET, CARONDELET, MO**

Ms. KERR. Thank you, Senator Kennedy.

First, let me convey to you both, personally and on behalf of the population we serve, our appreciation for your kind invitation to appear before you today on this important matter.

I'm sure that our perspective, based on local conditions and individual needs of our patients, will help you fully understand the near desperation and frustration felt by health centers across the country as attempts to care for those in need are thwarted by paralyzing burden of the current piecemeal approach to receiving health benefits for many families.

The Federally-funded community health centers were established in the mid-1960's. It is comprised of community primary care centers operated by community-based, not-for-profit corporations who service low and moderate income communities plagued with numerous and medical—numerous medical needs with a minimal compliment of medical providers. Presently, over 600 community health and migrant health centers are the main source of health care for nearly one million—six million Americans which include 1.5 million women of childbearing age and 2 million children.

My centers were created under Federal legislation to provide primary care services to low and moderate income families in which there are not enough available primary care physicians and programs. One center is located in the city of St. Louis and the other center is located in St. Louis County. Last year, 15,000 patients were seen which resulted in 60,000 visits at our centers. Consequently, we see, firsthand, the impact of inadequate health insurance coverage on the utilization of health care services.

Specifically, it is clear that uninsured and under-insured individuals face significant barriers in maintaining their health which include the following:

- Limited access to care, particularly maternal/child services;

- Inability to comply with drug therapy due to the cost of prescription drugs;

- A general reluctance to use primary and preventive health services; and

- A reliance on the emergency room as a regular source of care.

The inadequately insured population that uses our health centers fall into three broad categories.

The first, low income persons with no public or private health insurance. This group comprises 30 percent of the users of People's Health Centers, Incorporated, and is composed primarily of women and children. Of this group, approximately 16 percent are working, but have no coverage provided by their employers.

The second category is the employed individuals with inadequate health insurance coverage. This group represents approximately 15 percent of the population we serve. Generally, these individuals are covered by policies that exclude or place high deductibles on primary care services, payments for prescription drugs, and for dental care, and unfortunately, many times, they think they have adequate coverage.

And then the low income, elderly Medicare beneficiaries who lack supplemental health insurance and are not covered by Missouri Medicaid. Our centers have seen a considerable increase in the percentage of low income elderly users, and in 1988, this group accounted for 11 percent of all of our patients.

And, finally, we know that there are inadequately insured persons who may not be low income, but who are at risk of becoming medically indigent if struck by high costs of illness or accident, as you just heard from one of the witnesses. There's no real debate about the fact that the lack of affordable health care has reached crises proportions affecting all of us. Uninsured and under-insured people suffer with serious untreated health problems often because they avoid seeking health care from traditional institutions until an emergency crisis arises. I'll demonstrate this for you, and I'm giving you three examples from the People's Health Centers, but we could give hundreds and hundreds.

Recently, a 30-year-old woman, mother of four children, living with her employed husband with no health insurance, presented with facial numbness at the county site of which we toured this morning. She was referred to the emergency room, was seen there and sent home without being diagnosed with a problem.

Our physician—and I'll name her because you met her this morning on the tour—Dr. Michaels, a very committed physician at the county site, followed up on this patient, called her at home and said what happened at the ER? She found that the patient had not been diagnosed, and was sent home with no care.

She then made an appointment at the neurology clinic and sent her there. She was seen and sent home the second time without being diagnosed or treated.

Dr. Michaels followed up on her for the second time. She then through her political pull got this patient into one—private clinic in one of the private hospitals for a workup of which she was diagnosed as having a brain tumor.

She was then followed by Dr. Michaels, again, and she was sent back to the previous place of where you—she was sent to the neurology clinic, and then, with the diagnosis of brain tumor, received surgery, has had the tumor removed, and is now recovering. It took 10 days to take this severe case into care before it became a catastrophic illness for this mother of four children.

A second case was a middle-aged under—uninsured man who worked for a construction company for many years never receiving—never being insured by his employer, stayed at home until he had lost 50 pounds, came into the center very weak, was diagnosed with cancer, lived for 1½ years, was seen in the hospital on many occasions, and eventually died. And this is an example of the patient staying at home until they become severely ill before they will come and get free care.

And the other is of a pregnant woman who works and is uninsured. When called about her prenatal visits, she will tell the nurse and provider, "I'm not coming this week because I cannot afford to pay for my services."

We don't demand payment. We have our patients on a sliding-fee scale, and those who cannot pay can get served, but this young woman will not use the center without coming with a payment for her services which is usually a \$10 fee on a sliding fee scale. And we know what happens when women don't come in for care early. The impact it might have on the infant in terms of being low birth weight and having other significant problems.

These cases are typical of the many problems that befall the uninsured families at People's.

The current situation is absolutely untenable. We're weathering the storm as best we can, but, like most of our patients, we're on fixed—extremely tight budgets ourselves. Although we treat all of these patients, it is clear that the cost of inpatient services to this population is borne by the hospitals uncompensated care which drives up the costs of health care throughout the Nation.

In addition, it is important to note that Medicaid eligibility in Missouri requires that individuals meet income standards for cash grant assistance; therefore, there is simply no option for inadequately insured wage earners to acquire coverage under the existing Medicaid program, leaving the purchase of individual health insurance as the only way of protecting against out-of-pocket payments for health.

In summary, as proud witnesses have described, the continued failure to require that basic coverage be provided by employers to all of their employees will continue to destabilize the health care delivery system through cost shifting and will continue to negatively impact on the health of the community.

The CHAIRMAN. Thank you very much. We will hear from Ms. Weinell and then we'll come back to questions for both if we could, please. Thank you very much.

Ms. WEINELL. It's a pleasure to have you here, Senator Kennedy, and we thank Congressman Clay for showing you around St. Louis. It's an honor to have you here and especially to talk about this bill.

I would like to let you know that all of us at Family Care Center, the board, the staff, and the patients support this bill. We hope that this bill will be the first step toward a national health insurance program for every American or a national health service for every American which will show for sure that health care really is a right of all Americans.

We are also, as Betty described, a Federally-funded health center. We have about 10,000 patients who come to our center. And I'd like to give you just kind of a composite picture of the people



who come. As you noted, we serve the working poor and the poor in South St. Louis. We have at this time, of the patients coming into our center, over two-thirds of them at the level of poverty or below. We have 59 percent of our patients, more than half, who are on the sliding-fee scale that Betty talked about, and of that group, two-thirds are at the level of poverty which means that they are paying the very least. And we're also hearing from those patients, through studies of our patients satisfaction with our center, that 22 percent frequently have trouble paying our lowest rates. So that the cost of poverty is obviously very great.

I would also like to point out that among the people who have insurance, we have two-thirds of them who make—excuse me, for a family of four who make less than \$17,500. Now, if those people get into any kind of catastrophic conditions, they are in very serious trouble.

The other information that I could share with you about our patients is that 38.5 percent are unemployed. We used the Federal definitions for unemployment of the unemployed who have been looking for work in the last 4 weeks; the discouraged worker who's given it all up; and the people who have never been able to get into the work force. This is a large group of people who have no resource for care because, as Betty points out, primarily in our State, they can't get on Medicaid because of their low income and out of work.

Now we universally agreed that low-income people are at risk for being uninsured. It is the case that even though 41 percent of our patients work, we have only 9 percent of them insured.

Now our experience is very much——

The CHAIRMAN. Let's hear that figure once again because I think it's important.

Ms. WEINEL. Forty-one percent of our patients work fulltime.

The CHAIRMAN. Full-time work.

Ms. WEINEL. They claim full-time work and only 9.8 percent of them have insurance. That's a pretty big number.

The CHAIRMAN. Yes, that certainly is.

Ms. WEINEL. Now the catch in this, I think we should discuss for a minute. Experience has shown us that the people who say they're insured do not have coverage for primary health care which is what the community health centers deliver. What we find is that we become the coinsurance and the deductible for the more expensive hospital and other tertiary care.

We would like you to consider first dollar coverage for primary health care in your bill, Senator Kennedy, and that you would reserve the deductibles and you would reserve the coinsurance for the secondary and tertiary levels of care so that all people truly have access to care and are not held back by a financial barrier.

We find that being insured is not only related to income, but also employment, as I've just mentioned. And that if you would come into our center and you would say, "Well, you know, I'm unemployed now. I have worked, but I'm unemployed," that we would say, "Why aren't you working?" You would fall into the category, of course, of being a discouraged worker.



And there are three chief reasons that our patients say that they aren't working when they fall into the discouraged worker category.

One is family responsibility and I think the Hoffman's portrayed that very graphically. There is a lack of day care for children and for babies because as soon as a woman who is on expanded Medicaid, for which we're all appreciative—as soon as she goes off of that, she has no health coverage, and she must go off to work because, in our State, she's not going to be eligible for AFDC benefits. Therefore, she has to go out to work, but she has no place of day care for an infant, much less the usual day care of age 2½ or 3. And finally, illness is a big deterrent to finding work.

Now being under-employed and 16 percent of our people are—we're calling under-employed because they can only get part-time work. I'm not even addressing the low salaries that the employed people have. But under-employed people and unemployed people who come to our center are living—82 percent of them, almost 100 percent, are living at 150 percent of poverty or less. These are people who had jobs, and, if they had been eligible for Cobra—if they had actually had insurance and been eligible for Cobra, they couldn't afford to pay it. So, there is a group of people that somehow or another, as I see in your bill, we will get them covered, but later to—toward the year of 2000. Hopefully, our country can have a conscience to speed that up and get insurance for the unemployed.

Congressman CLAY. I wouldn't wait on it. [Laughter.]

We've got a President who promises a more kind and more gentle Nation and yet he vetoes minimum wage bill. I wouldn't count on the conscience of this Nation arising for purposes other than maybe those promoted by groups such as the National Rifle Association.

Ms. WEINEL. I would like to hope that we in the 1990s would start moving into an era where we see movement or at least glimmerings of society saying, "Yes, we do have to take care of other people."

I've been asked to talk about our—a State study that was done several years ago, Senator Kennedy, for Mediassist which was a bill we tried to pass here in Missouri to help the uninsured. On telephone surveys to see—could this go through if it were a tax or whatever method we would use, there was in the State of Missouri a positive response to people who said, "Yes, we think that the uninsured and those without health care should get it." Now we've never quite gotten our bill through, but I think that's related to a complexity of things—as politics always is. But I think that there might be some hope in our society, and I would like to hope it's going to come before the year 2000. I don't know. You all have a much more national pulse on things. I'd be curious to hear what you're thinking about that.

And then finally, I would like to support what Betty said. There are those of us who are serving in the public sector and we are as poor as our patients. There is no way that we can cost shift; we have to pick up all the needs of the people. At our center, we have turned away 2,000 new patients this year. We're filled up; we don't have any room for more people, and we've turned away over 2,000

new patients this year. We also cannot cost shift to say, "Well, if we get a disallowance in Medicaid, Medicare, or by any of the insurance companies, that someone else can pick it up." And it's part of the reason I would like to call for, again, the first dollar coverage for primary health care which, of course, includes having prevention in it. We would also like to say, again, that if we could transfer the deductible and copay to hospitalization in the belief that primary health care can reduce such secondary and tertiary care, we believe this would be a good thing for people.

Now let me speak just a moment about our study on the uninsured in Missouri. The uninsured in Missouri fell into three categories: Low income, lack of adequate health insurance whatsoever within the family, and very high health care needs.

The State, as a whole, had 27 percent of its population, a little more than one-fourth, who were under 150 percent of poverty, and, in those homes that had children, almost 50 percent—it was really 41 percent of those homes had children in them that were in 150 percent of poverty or below. So we know that our elderly and the children throughout this State are the ones that are hard hit by poverty and of being uninsured.

Again, the question was asked, "Why are you uninsured?" And for the St. Louis area, 20 percent of those people responding said they lost insurance when they lost their job; 16 percent said they never had any insurance when they were on their job; and another 26 percent said the insurance was too expensive. There had to be a copay in it and it was too expensive for them to handle, and, another 12 percent were the ones who were always at risk that can't get insurance like we have heard about today. Twelve percent simply could not get insurance.

Now the worsening economy in our State has made things pretty tough not only here in the St. Louis and the urban areas, but also in the rural areas. Northeast Missouri was found to have a 50 percent increase in people who entered into the poverty levels economically. The people who were at the lower end of the income scale, we found, were three times as likely not to have any insurance at all in our State.

Then we also found a group that were in high care—high health care risks. And these are some of the people that we have heard from today, and they also need a very special kind of insurance for the catastrophic conditions that they have.

This is just a brief summary and in the material for the prepared text, I have the summary of that whole study which you can look at in more detail.

Thank you for the opportunity to tell about it.

[The prepared statement of Edna Dell Weinel (with attachments) follows:]

**PREPARED STATEMENT OF EDNA DELL WEINEL, EXECUTIVE DIRECTOR  
FAMILY CARE CENTER**

Senator Kennedy, I am Edna Dell Weinell, Executive Director of Family Care Center. We stand in support of Senate Bill 768 which would provide basic health benefits for all Americans and hope that this bill is the first step in providing equity in health care for all Americans by means of national health insurance or national health service, or any other legislative initiative which insures health as a right for every American.

The Family Care Center is a federally funded Health Center providing primary health care services to approximately 10,000 people. The people coming to our Center need the assistance this bill could provide. Let me draw a composite picture of the person coming to Family Care Center:

16.4% are members of a minority group predominantly Black,

Hispanic, and Asian, while 83.7% are white;

63.3% of the patients have incomes at or below 100% of poverty;

59.0% of the patients self pay for services on the sliding fee scale;

36.1% of the patients who work have family incomes of \$12,000 or less;

68.7% of patients with insurance have family incomes <-\$17,500;

38.5% of the patients are unemployed.

It is universally agreed that families with low income are more likely to be uninsured. Of the 10,000 patients coming to this Center, 9.8 report insurance coverage. Experience has shown that there is not coverage for primary care, and that our cost becomes the deductible for more expensive secondary and tertiary care. Would you consider first dollar coverage for all primary health care services and reserve the deductible and co-payment for the secondary and tertiary care?

Continuous and comprehensive primary care does reduce the more serious problems of disease and disability when it is geographically and financially accessible.

Being insured is not only related to income but also to employment. You will notice on the circle graph which illustrates employment status, of our 10,000 patients 41.1% are employed full time, but only 9.8% have insurance.

If you come into our Center as an unemployed person and you have not looked for work in the last four weeks, you are termed by the federal government a "discouraged worker". The reasons we find that you have not looked for work are because of:

1. family responsibilities,
2. lack of day care for children, and/or
3. illness.

Among the underemployed and unemployed families, 82% live at or below 150% of poverty. If these workers were eligible for COBRA they could not afford it. The impact on families is very great because this group has children in the home.

In speaking for first dollar coverage for primary care, I would indicate that many Community Health Centers and other public providers do not have a way to cost shift to another patient group or third party payor, thereby picking up the cost of care to low income people. Instead we have patient charges discounted by the sliding fee scale and disallowances by Medicaid, Medicare, and insurance companies. The second illustration is a bar chart which compares method of payment with the fee collected. Clearly there must be a subsidy for providers like ourselves to cover those persons still without insurance as well as the insured patient with deductibles and co-insurance costs if the bill does not provide primary health care.



As an employer of 60 people, the cost of employee health care has been increasingly a high cost item in our budget. It has been this Center's experience that for employees to use the insurance benefits there will be a subsequent increase in the premium. This Center has always provided coverage for family members based on the philosophy that all people have a right to health care. However, we have not been able to afford health care benefits for part time employees based on the dollar cost and the experience that added use of benefits which would effect our experience rating.

A summary of escalating insurance costs follows:

<u>Year</u>	<u>Insuror</u>	<u>Annual Cost</u>	<u>Employees</u>
1984	3rd year of a contract	\$ 46,794	25
1985	New company	\$ 53,007	28
1986	Same company	\$ 63,633	33
1986(Aug)	New company*		
1987	Same company	\$ 67,891	41
1988	Same company	\$ 74,220	39
1989	Same company	\$122,519	42

\*At the end of the contract year, the premiums would have increased by 50%.

Present deductible and co-insurance for single \$700; for a family \$1700.

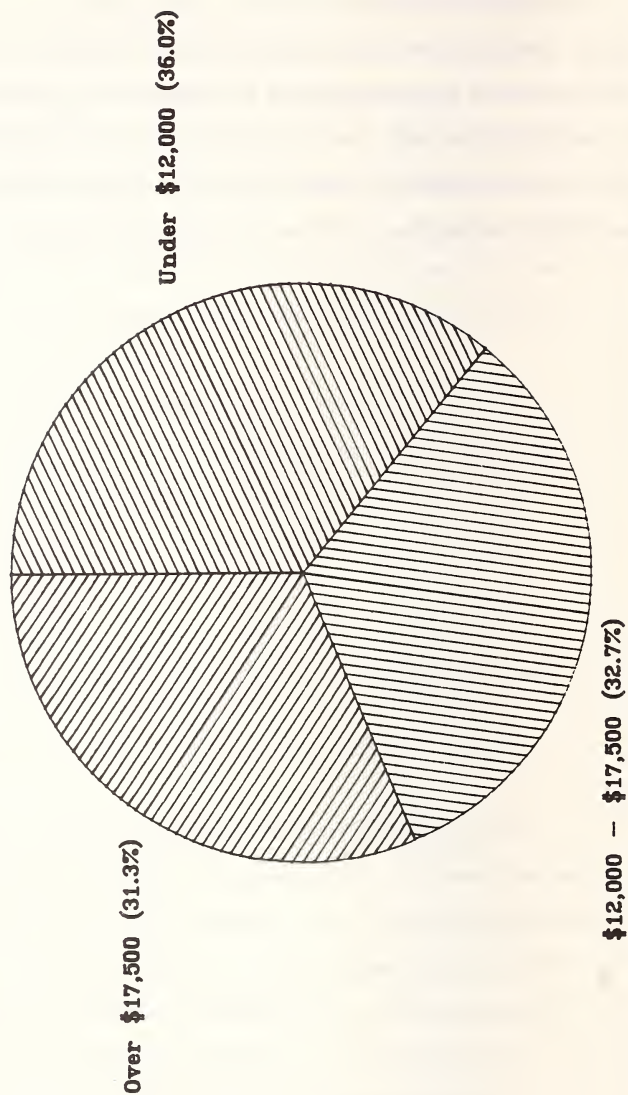
The low rate for premiums represents a first year with a new company. The increase in premiums is tied to added employees, but more importantly to employee use of the benefits. This use of the benefits included primary visits to physicians, normal pregnancy and delivery, and a minimal amount of speciality outpatient care. The situations which contributed to the increases included: surgery for cancer, accidental death, injuries, premature twins, and mental health services, including substance abuse care which can cost \$15,000 for a month's hospitalization.

Finally I would share with you that not-for-profit organizations have difficulty obtaining bids on health insurance. No one in the insurance world has been able to give an explanation of why.

In summary, we support the bill. We respectfully request first dollar coverage for primary health care which includes preventive services and we ask consideration to transfer the deductible and co-pay to hospitalization and speciality services in the belief that primary health care can reduce secondary and tertiary care if such primary health care is geographically and financially accessible.

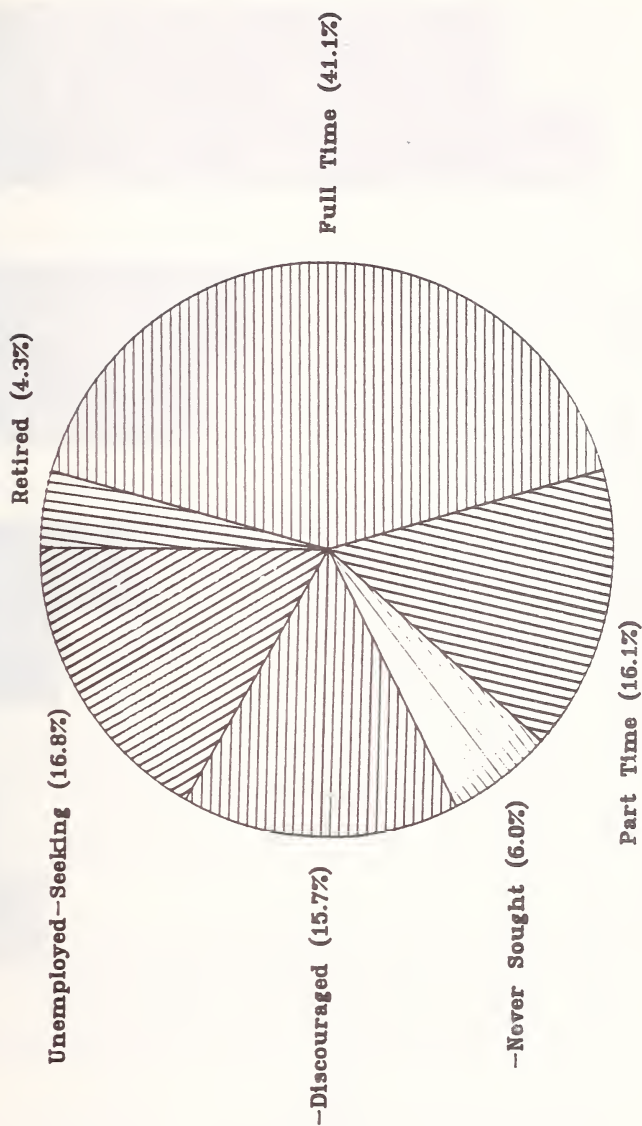
# FAMILY CARE CENTER OF CARONDELET

Annual Income of Insured Patients



# FAMILY CARE CENTER OF CARONDELET

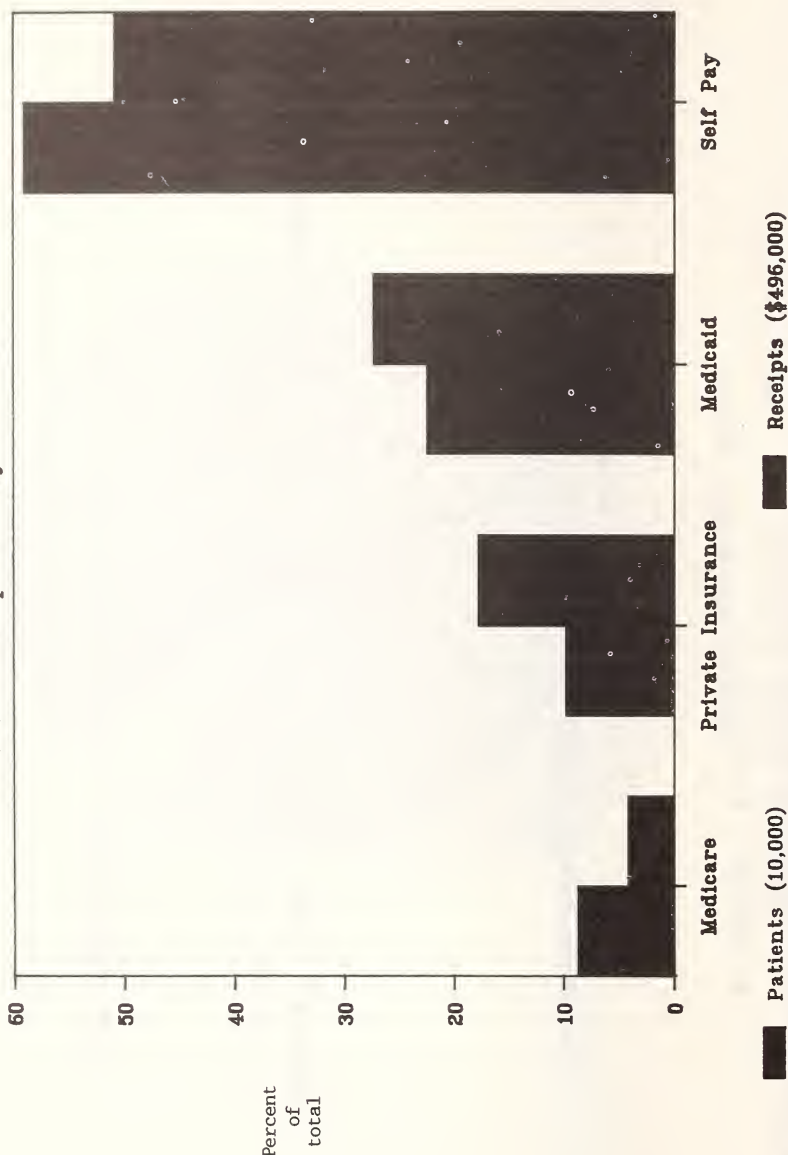
## Current Employment Status





# FAMILY CARE CENTER OF CARONDELET

Patient Receipts vs. Payment Status



Status of Uninsured in Missouri

In 1986 a study of medical indigency in Missouri was based on several risk factors:

- low income;
- lack of adequate health insurance coverage; and
- high health care needs.

Low Income

Using federal poverty guidelines, families with incomes at or below <100% of poverty were designated as poor, and families with incomes up to 150% of poverty were designated as working poor. The results show

- \* 27% of the state's population falls below 150% of poverty
- \* 37% of the state's elderly fell below 150% of poverty
- \* 41% of the households below 150% have children.

Uninsured

Of all the people in a household, some may be covered by Medicare (28%), Medicaid (5%), while 15% reported being uninsured sometime during the year. For those being without health insurance, the reasons included:

- |                                   |                    |
|-----------------------------------|--------------------|
| * lost insurance with lose of job | (in St. Louis 20%) |
| * no coverage through job         | (in St. Louis 16%) |
| * too expensive                   | (in St. Louis 26%) |
| * were refused coverage           | (in St. Louis 12%) |

Persons in low income families are much more likely to be without insurance than those in higher income households. Over one quarter of all persons in households with incomes below 150% of the federal poverty level were uninsured at some time during 1985, as compared with only 7% of the population above that income level. More than one third of all persons living below the poverty line were uninsured during 1985.

A worsening of the economy in certain areas of the state since 1979 has likely increased the size of the uninsured population in those areas. For example, the northeast section of the state, which has one of the highest rates of uninsured persons of all the state's regions, is estimated to have had nearly 50% increase in the relative size of its low income population. This is probably the direct result of the current farm crisis being experienced by the northern part of the state.

Over 60% of households with an uninsured member during 1985 reported the head of the household to be employed at the end of the year. However, families in which the head of the household was unemployed were three times more likely to have an uninsured member than households whose head was employed full time.

Children were more likely to be uninsured than adults, while the elderly, because of the presence of Medicare, were much less likely to be without insurance than the rest of the population.

### The Underinsured

Having health insurance does not necessarily provide complete financial protection against the cost of illness. Some policies may exclude certain services, place limits on what is covered, or require considerable patient cost sharing.

The inadequately insured population can be divided into these groups:

- \* low income non elderly persons with inadequate private health insurance;
- \* low income elderly person covered by Medicare who lack supplemental private insurance or who are not also covered by Medicaid; and,
- \* persons who do not meet the definition used in this report of "low income" but who are inadequately insured and at risk of becoming medically indigent if they incur catastrophic expenses as a result of a serious illness or accident.

### High Health Care Needs

~~Families in which there was a person who had a serious medical condition, disability, or handicap that required medical treatment or hospitalization on a regular basis reported a greater likelihood of having an uninsured member than did the general population.~~

One fourth of all Missouri families below poverty said they had no usual source of medical care, as did a similar percentage of households with uninsured members.

Adults in households with incomes below poverty reported visiting a doctor significantly fewer times in the past year than adults in households between 100% and 150% of poverty (3.8 vs. 5.6 visits). Adults in uninsured households also had low utilization rates.

Hospital admission rates for adults either in families under poverty or in uninsured households were also very low.

### Resources

- . Missouri had expanded Medicaid to include pregnant women and children to age three years at the 100% of poverty level.
- . A Prevention of Mental Retardation Program reimburses hospitals for certain high risk conditions of pregnant women and their infants.
- . Missouri Crippled Children's Services diagnoses and treats specific problems of children.
- . Missouri Department of Health has a Case Management Program for pregnant women.
- . Certain hospitals which serve a disproportionate number of poor receive higher reimbursement rates.
- . Hospitals in St. Louis serve more low income people with a special rate than elsewhere in Missouri.

## MISSOURI INDIGENT HEALTH CARE STUDY

### EXECUTIVE SUMMARY

#### A. Purpose of the Study

Although the United States has one of the most well developed health care systems in the world, a substantial portion of its population is believed to lack either the insurance coverage or financial resources to afford needed care. These persons are often referred to as the "medically indigent."

State government historically has played an important role in helping the medically indigent gain access to needed health care. Recognizing that the current changes in the health care system may create increased access problems for this population, the Missouri Legislature commissioned a study of the state's medical indigency problem. This study was conducted by Health Systems Research, Inc., a Washington, D.C.-based policy research firm specializing in health care financing issues.

The objectives of this study are:

1. To identify the size and characteristics of the medical indigent population in the states;
2. To examine the health care utilization and financing patterns of this population;
3. To analyze the publicly supported health care programs operating in Missouri;
4. To explore the impact rising malpractice premiums may have on the low-income population's access to physician care;
5. To determine the extent to which care to the medically indigent is provided in public, private and children's hospitals in the state and to assess the impact of providing this care on the financial status of these facilities; and
6. To examine alternative methods of financing indigent health care in Missouri.

#### B. The Medically Indigent Population in Missouri

To determine the size and characteristics of the medically indigent population in Missouri, a telephone survey of over 4,000 households was conducted by Louis Harris



and Associates, Inc. under subcontract to Health Systems Research. This survey collected information on insurance coverage, health care utilization, and participation in public health care programs.

The results of this survey, coupled with state-specific census data and findings from other national studies, indicate that the number of persons in Missouri who are medically indigent or at high risk of being medically indigent is approximately 1,000,000 persons, or about 20% of the state's total population. These persons can be divided into the following groups:

- Approximately 617,000 persons who are without either public or private health insurance at some point during the course of a year;
- Nearly 300,00 non-elderly low-income persons with inadequate private health insurance that does not cover such things as physicians visits, prescription drugs and dental care;
- 55,000 low-income elderly persons with Medicare coverage who have no other insurance for the substantial portion of the aged's health care expenses not covered by this program; and
- Over 36,000 persons above 150% of poverty who will incur out-of pocket medical expenses in excess of 10% of their family incomes.

With respect to the characteristics of the uninsured population, the indigent health care survey yielded the following information:

- Persons in low-income families are much more likely to be without insurance than those in higher income households. Over one-quarter of all persons in households with incomes below 150% of the federal poverty level were uninsured at some time during 1985, as compared with only 7% of the population above that income level. More than one-third of all persons living below the poverty line were uninsured during 1985.
- A worsening of the economy in certain areas of the state since 1979 has likely increased the size of the uninsured population in those areas. For example, the northeast section of the state, which has one of the highest rates of uninsured persons of all the state's regions, is estimated to have had nearly 50% increase in the relative size of its low-income population. This is probably the direct result of the current farm crisis being experienced by the northern part of the state.
- Over 60% of households with an uninsured member during 1985 reported the head of the household to be employed at the end of the year. However,

families in which the head of the household was unemployed were three times more likely to have an uninsured member than households whose head was employed full-time.

- Children were more likely to be uninsured than adults, while the elderly -- because of the presence of Medicare-- were much less likely to be without insurance than the rest of the population.
- Families in which there was a person who had a serious medical condition, disability, or handicap that required medical treatment or hospitalization on a regular basis reported a greater likelihood of having an uninsured member than did the general population.

#### C. Health Care Access and Utilization by Missouri's Low-Income and/or Uninsured Population

The indigent care survey of Missouri households indicate that poor and/or uninsured families encountered problems in accessing health services much more often than other segments of the population.

Over one-fifth of all families with incomes below 150% of the poverty level reported encountering some problem in the past year -- they needed care but didn't receive it, were refused care, had to rely on charity care, or were unable to pay their medical bills. Thirty percent of households with uninsured members encountered similar access problems. In contrast, only 5% of households above 150% of poverty reported any of these problems.

Other findings from this survey that provide evidence that poor and uninsured populations lack adequate access to and coverage of health care include:

- One-fourth of all Missouri families below poverty said they had no usual source of medical care, as did a similar percentage of households with uninsured members.
- Adults in households with incomes below poverty reported visiting a doctor significantly fewer times in the past year than adults in households between 100% and 150% of poverty (3.8 vs. 5.6 visits). Adults in uninsured households also had low utilization rates.
- Hospital admission rates for adults either in families under poverty or in uninsured households were also very low.

- Only 14% of pregnant women in households with income below poverty were reported to have some ~~type~~<sup>kind</sup> of coverage for their prenatal care.

#### D. Publicly Supported Health Care Programs in Missouri

Forty-one different publicly supported programs either finance or directly provide health care for low-income persons in Missouri. These programs can be divided into seven categories:

- 4 entitlement programs that provide health insurance-like coverage of a relatively broad array of health services for those persons meeting certain eligibility requirements.
- 17 maternal and child health programs that offer select services targeted to the needs of women and children.
- 4 general health programs that support the direct delivery of health services through certain public or publicly supported providers.
- 9 disease-specific programs that provide health services targeted to persons with specific, usually chronic, medical conditions.
- 1 other health-related program that provides food supplements and health assessments for women and children.
- 3 hospital support programs that provide direct financial support to hospitals in the state.
- 3 mental health programs that provide inpatient and outpatient services for individuals with mental health problems or who are mentally retarded.

In 1985, about \$1.7 billion was spent in Missouri through these programs, of which over \$1 billion were federal funds. Of the remainder, state expenditure totalled \$535 million and local government expenses \$71 million. The bulk of these expenditures were made through the federal Medicare program, the federal-state Medicaid program, and the state's mental health programs. Expenditures made under all programs covered a wide variety of population groups and services. Two-thirds of all expenditures, however, are used to finance costly inpatient hospital care and long-term care services.

The manner in which services are delivered also varies significantly under these different programs. Certain programs deliver services directly through state facilities. Other enter into contracts with local health departments or private providers to deliver the services. The two largest programs – Medicare and Medicaid – will

allow any qualified provider to render care.

#### E. Physician Malpractice Premiums and Access to Care

A survey of Missouri physicians conducted as part of this study indicated that rising premiums resulted in changes in many physicians' practices. These changes included:

- increased fees;
- more conservative practice styles;
- avoidance of high-risk patients;
- a reduction in the number of Medicaid patients seen by physicians who already had relatively small Medicaid caseloads;
- a refusal to accept new low-income patients;
- physicians electing not to provide care in local health department-sponsored clinics.

Although an increase in malpractice premiums was cited as a major factor in these changes, low reimbursement rates also were cited frequently as a reason for physicians limiting the number of Medicaid patients they would see.

While the reform legislation recently passed by the Missouri legislature (S.B. 633) is certainly expected to slow the precipitous rise in medical malpractice premiums, it is uncertain whether it will be able to repair the damage that already appears to have been done to low-income Missourians' access to physician care. Of particular concern is low-income pregnant women's access to vital prenatal and obstetrical care, which has decreased considerably in recent years and may continue to worsen. Unless a way is found to provide care for this high-risk population, the state may experience increases both in its infant mortality rates and its future expenditures for low-income children with disabilities that could have been prevented with adequate prenatal and obstetrical care.

#### F. Hospital Uncompensated Care

The extent to which Missouri hospitals provide care to the medically indigent and the impact of providing that care has on hospitals' financial status is examined in this study using data from the Missouri Hospital Association and from a special survey of Missouri hospitals that was conducted as part of this study.



The term "uncompensated hospital care" is made up of three components:

- contractual allowances, which is the difference between hospital charges and the amounts actually paid by insurers;
- charity care, which is the value of care provided to persons from whom the hospital does not expect to receive payment -- usually poor, uninsured persons; and
- bad debt, which is the unpaid portion of a hospital's charges billed to persons who are considered able to pay.

Overall, the amount of uncompensated care provided by Missouri hospitals doubled between 1980 and 1984. The extent to which three components increased varied substantially across public, not-for-profit, and for-profit hospitals. For example, charity care and bad debt levels more than doubled in public hospitals during that period, while they increased by only 58% in not-for-profit hospitals. In contrast, contractual allowances increased much more rapidly in private hospitals than in public facilities.

In spite of these increases in contractual allowances, payments by private insurers generally exceeded the patient care costs associated with these patients. In some cases, however, payments from public programs -- including Medicaid -- did not cover patient care costs. Children's hospitals appear particularly hard hit by low public program reimbursement rates.

Data from the survey of Missouri hospitals, conducted as part of this study, indicate that rising charity and bad debt burdens are having a serious effect on the financial status of certain types of hospitals in Missouri. Ten of the 23 public hospitals responding to this survey reported deficits in 1984, double the number with deficits in 1980. These public hospitals with deficits provided three times more charity and bad debt care than responding public hospitals without deficits. By comparison, only two of the 30 private, non-children's hospitals reported deficits in 1984. One of the state's three children's hospitals reported a deficit in 1984, although the other two were forced to cover operating costs by drawing other revenue services, including capital reserves.

Since 1980, seven public hospitals in the state have been sold to private organizations, while another four have been closed. At the same time, the number of for-profit hospitals in the state has doubled, increasing from 12 to 24. The increasing deficits faced by public hospitals may foreshadow even further drastic changes in the composition of Missouri hospitals.

G. Alternative Methods of Providing and Financing Health Care For Low-Income Missourians

Based upon a review of programs and policies adopted by other states and the current configuration of public health care programs in Missouri, a number of programmatic changes are proposed to improve the medically indigent's access to needed health services.

These recommendations focus on state program and policy changes that: (1) extend coverage to low-income groups with high health care needs, (2) provide care in a cost-effective manner, and (3) make maximum use of available federal funds. They include:

- Medicaid program expansions;
- the integration and coordination of public programs providing care to pregnant women;
- the reexamination of restrictions on the activities of physician extender personnel;
- the expansion of Medicaid case management activities;
- increased assistance to local health departments; and
- changes in hospital reimbursement and reporting requirements.

A number of potential revenue sources are identified to finance the increased costs associated with these activities. Federal funds can be used to support a substantial portion of these additional expenditures. In fact, certain recommendations involve no increase in state expenditures, but will result in an increase in federal dollars coming into the state.

Among the options identified to generate additional state revenues to support indigent care activities, increases in the state's excise taxes on tobacco and alcohol appear particularly promising. Increasing Missouri's current tax rates to the average for states will not only reduce the use of these potential health hazards but is also estimated to result in a net increase in state revenues of over \$23 million.

## MISSOURI INDIGENT HEALTH CARE STUDY

### RECOMMENDATIONS

Recommendation 1:                      Expand the Missouri Medicaid program by including a medically needy component to cover pregnant women and children.

The expansion should extend Medicaid coverage to pregnant women and children in households with incomes between 100% and 133.33% of the AFDC maximum payment standards. This would mean that pregnant women and children in households with incomes above AFDC levels but below 50% of the poverty level would be eligible for Medicaid but not for AFDC cash payments. These families would be required to meet eligibility limits concerning financial assets. Also eligible for Medicaid would be pregnant women and children in households with incomes above 133.33% of AFDC maximum payment levels but who incur medical expenses that would reduce their income down to the eligibility levels.

The addition of this coverage would make Missouri the 40th state that has established a medically needy component within its Medicaid program. Expansion of Medicaid eligibility for pregnant women and children has been strongly supported by the Southern Governors' Association, while the National Governors' Association has advocated increased federal flexibility to allow expansion of the Medicaid population. Other professional organizations, such as the American Hospital Association, have also recommended a specific expansion of the Medicaid population to cover persons without insurance.

Based upon the experience of other states described earlier, a preliminary estimate of the budgetary impact of the expansion of the Missouri Medicaid program to include a medically needy program for pregnant women and children is an increase in program expenditures of approximately 3% or about \$17.5 million. Of this amount, federal funds would support about \$10.5 million, with the state contribution being \$7 million. It should be noted that these costs are estimated for a fully operational program. In the first several years, expenditures are likely to be below this level.

Recommendation 2:                      Develop an integrated perinatal program for the state's low-income population through improved coordination of the Medicaid, Prevention of Mental Retardation (PMR) and Prenatal Clinics programs.

Missouri currently operates very different programs that finance or provide prenatal services for low-income pregnant women. Through its Prenatal Clinic program, the state supports the prenatal care activities of local health departments. Its PMR program pays full charges for case-managed care provided to a limited number of pregnant women with certain high-risk conditions. The Medicaid program reimburses at substantially lower levels for prenatal and delivery services for eligible women.

Several problems appear to be associated with the present arrangement:

- As discussed in Chapter VI, malpractice insurance increases, low reimbursement, and other economic considerations may be reducing the number of physicians willing to provide obstetrical care to low-income women. In some areas of the state, the availability of physicians to care for this population may be a critical problem.
- For many of the same reasons, local health departments may find it increasingly more difficult to get physicians to participate in their prenatal clinics.
- Physicians' unwillingness to accept Medicaid's low reimbursement rates for obstetrical care may deter the enrollment of eligible persons in the program. These individuals may therefore be cared for through programs supported entirely with state or local funds.
- The PMR policy of paying a provider's full charges may not represent the most efficient use of limited program funds. Negotiated arrangements for case management and treatment at rates below full charges could allow more persons to be served without necessarily compromising access to needed care.

In developing a more cohesive statewide strategy for providing perinatal care for low-income women, Missouri should:

## 2.1 Expand Medicaid eligibility for pregnant women through:

- coverage of pregnant women in households meeting AFDC financial standards but not other requirements, as mandated by P.L.99-272;
- continued eligibility for pregnant women for 6 months after the end of the pregnancy, as also mandated by P.L.99-272; and
- the addition of a medically needy program for pregnant women and children, as described above;



2.2 Reduce the disparity between Medicaid and PMR payment levels for obstetrical care. Medicaid payment rates for physicians' services should be increased, in an effort to make prenatal and delivery services more accessible to program recipients. Similarly, PMR should pursue making better use of limited program resources by setting rates through either a contract or negotiation process that reflects some savings from full charges.

2.3 Place increased emphasis on case management of high-risk Medicaid pregnancies. P.L.99-272 provides states with the option of reimbursing for case management services for a selected population. Missouri should explore the possibility of covering such a service for high-risk pregnancies in order to bring the nature of its coverage of this group closer to the case-managed care provided under the PMR program. The state may wish to explore the possibility of receiving a federal waiver to contract only with certain qualified provider to care for these high-risk cases.

2.4 Coordinate eligibility criteria for the Medicaid and PMR programs to maximize use of federal Medicaid dollars. The Medicaid expansions identified earlier will result in an increase in the number of women who might otherwise be covered under the PMR program.

Recommendation 3:      The state should reexamine its current requirements concerning the functions and supervisory requirements of certified nurse midwives and other physician extenders.

In areas of the state where few, if any, physicians are available or willing to provide for the health care needs of pregnant women and other low-income persons, these other types of medical personnel might be able to play a very important role in caring for this population.

Recommendation 4:      Continue the careful development of primary care case management systems for Medicaid recipients.

Preliminary results of the state's case management demonstration for AFDC-related Medicaid recipients in Jackson County indicate that such systems have the potential for managing program utilization and expenditures while maintaining access to needed services. The state should explore expanding these activities into other areas of the state, particularly St. Louis City.

To ensure that these systems manage costs while maintaining access to needed quality care, the state must proceed carefully in program design and selecting providers and continue to play an active role in monitoring systems performance.

Recommendation 5:      Explore ways in which the state can assist local health departments in providing for the personal health care needs of uninsured persons.

Not all low-income uninsured persons in the state are able or willing to receive benefits through the Medicaid program. For example, the financial resource limits of this program may exclude many uninsured persons in the farm communities of the state from eligibility. In some cases, the local health departments and area public hospitals may be able to serve as a primary source of personal health care services for these persons. The state should examine ways in which it can support these local efforts. A good example of this type of collaborative effort is the Missouri Department of Health's involvement in the development of consortiums of public and private health care providers in northwest and south central Missouri.

Other specific ways in which the state might assist local governments in caring for their citizens include:

5.1 Provide state-supported or state-purchased medical malpractice insurance protection for physicians providing services in local health department clinics.

A substantial number of physicians responding to the survey discussed in Chapter VI indicated that insurance concerns played a role in their decisions not to participate in locally supported clinics.

5.2 Give technical assistance to local health departments to help them coordinate and manage the care their clients receive.

The pilot testing of an information system being developed by the Department of Health that will provide patient-specific data on public program coverage, health needs, utilization and referrals might result in a product that could greatly improve the effectiveness of local health department activities.

5.3 Extend to local health departments the increased flexibility to establish nominal charges for certain services.

As discussed in Chapter V, the state has historically interpreted the provisions of 205.050 RSMo to mean the local health departments can neither establish income eligibility criteria nor charge for their services. While no one should be denied services for financial reasons, the increasing demand for services coupled with limited financial resources to provide needed services may make it appropriate for the state to reconsider its position and allow local health units to establish nominal charges for certain services. The Missouri Department of Health should establish guidelines specifying maximum levels for these charges and the types of services for which they may be assessed.

- 5.4 Provide local governments with the ability to establish, upon approval of the voters in their jurisdictions, revenue sources earmarked to support indigent care activities, in addition to their existing public clinic and hospital district taxing authorities. For example, HB 1096 would allow county governments and the City of St. Louis, upon approval of the majority of voters, to establish a two mill property tax to be used for indigent care activities.

Recommendation 6: Incorporate payments made to hospitals under the state's Hospital Subsidy Program into special Medicaid hospital reimbursement rates paid to hospitals serving a disproportionately large number of low-income persons.

Under federal regulation, state Medicaid programs are able to give special consideration in their hospital reimbursement methodology to hospitals that serve a disproportionately large number of low-income persons. The state currently seeks to achieve this same objective through its Hospital Subsidy Program. This program is currently financed completely with federal state dollars and federal matching funds do not apply. The transfer of program funds to hospitals through increases in their Medicaid reimbursement levels using Medicaid's disproportionate share payment provisions will more than double the amount of funds available to these hospitals. For example, had the FY1986 appropriation of \$1 million for the Hospital Subsidy Program been run through the Medicaid program, it would have generated approximately an additional \$1.5 million in federal funds.

Recommendation 7: Increase Medicaid reimbursement levels to the children's hospitals in the state.

The analyses presented in Chapter VII of this report indicate that current Medicaid payments to children's hospitals are not sufficient to cover the cost of providing care to Medicaid-covered children. Medicaid's provisions concerning reimbursement for hospitals with disproportionately large low-income populations might be used to target increases to these facilities.

Recommendation 8: Establish mandatory hospital data disclosure requirements.

At least 22 states have established some form of hospital data disclosure requirements. Many of these have focused on the disclosure of charge information to allow health care purchasers to make more informed decisions in today's increasingly competitive health care marketplace. Other states require hospital data for hospital rate-setting activities. An increasing concern about the maldistribution of the charity care burden across hospitals, coupled with a growing frustration over not getting complete information from hospitals in this area, has also moved some states to require hospitals to submit data on their uncompensated care activities.

As described in Chapter VII, only 40% of the hospitals in the state responded to the survey conducted as part of this study. The response rate from for-profit facilities was particularly low -- only 1 of 18 that were sent the survey responded. Some aggregate data were provided by the Missouri Hospital Association. Requested information that would have allowed the calculation of statewide charity and bad debt care on the basis of costs rather than charges was not provided, nor were data on gross or net hospital revenues that are necessary to assess the impact of establishing an assessment on hospital revenues as a means of financing expanded care to the medically indigent.

Should the state wish to be in a position to be able to review on an ongoing basis and in sufficient detail the uncompensated care activities and financial status of all hospitals in the state, including the for-profit facilities, a statutory requirement for the submission of the necessary information appears to be necessary.



The CHAIRMAN. Thank you. Thank you very much.

Let us discuss the people that you turn away. How would you characterize them?

Ms. WEINEL. They're primarily low income people and don't come until they're sick, or pregnancy is another case for coming. There are people, yes, who are sick and our center is filled up. We have to be able to get our established patients back in. When they get sick, the doctor has them come back in because they come with multiple problems, and we have simply had to refer these patients to the City Health Center which is some 60 blocks north of us—not particularly accessible, but that was our recourse.

The CHAIRMAN. Do they accept them?

Ms. WEINEL. They accept them on an acute walk-in basis, but the problem is they also have a long waiting time to be able to get into the regular service, so they're accepted for episodic care, but the continuous care that would make a difference is not available.

The CHAIRMAN. Has that changed in the last few years?

Do you find that, Ms. Kerr, as well? I mean do you find that there are people now that are overburdening your kind of facility, or have you talked to—

Ms. KERR. Oh, absolutely. As you are aware that the health center's national part has been kind of held at bay, and yet, the needs for more services have certainly continued in our communities. And while we're seeing a lot more patients than we've ever seen before, we're getting to a point where we're not having to refer some of them elsewhere.

The CHAIRMAN. OK. What is the principle reason that you're finding more people that are coming to the centers than before?

Ms. WEINEL. I think people are poorer than they have been. I also think that some positive things have happened about health. There's so much talk of it now on the TV that people are also struck with the idea that maybe they should go to a physician.

I think that we have talked about access—that there is access to health care, but I think that there is less access to health care in St. Louis because we have closed so many of the city clinics, and that has made a difference, in my view, for those of us who have family—who have community health centers.

Second, in St. Louis, Cardinal Glennon Hospital, which was a big resource for people to take their child for emergency sick care, has not only scaled that down enormously, but has closed its primary health care clinic. And this has put a lot of children out into the other resources.

The CHAIRMAN. You talked about the number of people that are working and yet, only a relatively small percentage of those have health insurance coverage. Are the number of people that are covered today who are working, getting to be a smaller number than previous years? Are you able to draw any kind of conclusion?

Ms. WEINEL. Well, I—

The CHAIRMAN. Or any impressions?

Ms. WEINEL. If I could use our health center as an example, Senator, we're also an employer. We pay what we consider a lot for insurance. This year we're paying \$122,000 for health insurance for 42 people. Now our deductible, I think, is very great. On individuals, it's \$700, and on a family, it's \$1,700 before the insurance

kicks in. Now our insurance took a huge leap this year, and I've documented it for you. I'll be glad to leave this piece of paper with you, the increases we've had since 1964. We took a big 52 percent leap this year and it's really based on our history. If one uses health insurance, the premiums go up. I don't care if you're using it for ordinary things like physicians and normal deliveries—the insurance goes up. If you have some genuine need to use it as we have had in the past—for employees who have had to have surgery, who have been in accidents, unfortunately, an employee was killed once by an accident, we had twin babies that were premature—all of the sudden, you see that history stays with us, and our premiums keep going up and up because of a history we have had whether the employees are with us or not. And I think all employers are like us—they aren't necessarily malicious of heart about insurance for people, but the cost is so high.

And I think Betty will bear this out that we also have trouble getting bids for insurance. We asked our insurance broker to get us some bids. He came back with a list of 14 or 15 names of insurance companies and only had two bids; the rest wouldn't bid because we're a not-for-profit organization.

Congressman CLAY. Let me ask our witness, Senator . . . When people have come before our committee we have tried to find out why there has been an escalation in costs. Everybody contends that he or she is making less now. The doctors say that they make less money than before; that it's not their responsibility. The private hospitals say it's not their's. The nonprofit hospitals say it's not their's—that they're just keeping up with costs. Where is this cost escalating other than the insurance rates? Do you know what's responsible for the increase in costs?

Ms. WEINEL. Well, I think it's the profit motive in health care. Everybody may deny that they're making money on health care whatever they're doing—whether they're selling equipment, drugs, whether they're personnel in it, or what—but there's a profit motive in health care in our country. And, until we wipe out that profit motive, we're going to pay more than all of the rest of the world, someday, put together if we keep the profit motive in health care. Certainly the insurance companies are not getting poor either through health insurance or malpractice insurance.

Ms. KERR. I would like to add, also, 8 years ago, 70 percent of our patients were on Medicaid. They're now—the Medicaid users are 50 percent of our population, and that other 50 percent falls in the category of the working uninsured, under-insured, and about 10 percent with no insurance. I think that's an indication. Now, we went from 2,000 users to over 15,000, so the state of the economy in the last 8 years is an indication that more people need our services.

What we found is, in our population of users, many of them not only hold one job, but two jobs—two half jobs, and you find that a lot in our communities especially in the service area of our particular health centers. Many of them work at chains where they only employ part-time employees where the cut-off is at the point where they might have to pay benefits, and it's just not unusual to find many, many of our patients working one and two, and sometimes three part-time jobs.

To get back on the costs, we also, as Edna Dell mentioned, we are employers. We purchase health supplies. We have seen a significant increase in what we have to pay for supplies in our community health centers, so we know that the cost is escalating.

But I think that the challenge here is that all of us will have to pay one way or another. These patients are going to be seen. They're coming to us sicker because they—many of them have been employed; have, at some point in time, had health insurance; feel relatively embarrassed about coming to centers that they feel should support the more under-insured individuals, and they stay home until they are very ill. The three case studies that I gave were some indication of that. The patients were ready to go into the hospital when they entered our centers, and yet, we're primary care providers. So what do they do? They end up at the hospitals. The hospital is going to have to bear the costs for these patients which will be cost shifting to the economy on us. And I think that when you talk about the spiraling costs, if we could get some kind of health care programs together that's insured—and I certainly support the bill that the Congressman and Senator is proposing—then we could get our patients in for primary care very early which is a lot cheaper than having our patients come in who are ready to go in with a catastrophic illness which is extremely costly to the community.

Congressman CLAY. You know the hospitals can only bear so much of the costs. Now Howard University, yesterday, announced they were going to lay off about 20 percent of their staff because they'd documented they had given away \$35 million in services free of charge last year. Hospitals can't continue on this basis. There's got to be something here more basic, because the records do indicate that physicians are making less money now than they made 5, 10, or 15 years ago. Many of the slots in the medical schools are going unfilled when 15 or 20 years ago, there were 14 or 15 applicants for every slot. They're going unfilled now. They're reducing the number of people they advertise for.

Somewhere, I don't know where it is, but we've got to pinpoint where this increased cost is. It's twice what the increase is for everything else in the economy, and I just have not been able to figure out where it is.

Ms. KERR. Well, I think if you look at the health care pie, you will find that a small proportion of that money goes into primary care. It is cheaper to prevent illnesses than it is to treat them, especially when they get out of hand. We know that if we can delay in-stage renal disease that we will save the State \$50,000 per year for dialysis on a patient. If we treat the patient for hypertension before they begin the in-stage renal disease, it's even a lot cheaper. We know if we get the mothers in for care—we know all of those things.

But I think you're beginning where we should begin, and that is, to cover them with health insurance. It costs money to provide health care on every level, but it's cheaper to provide it on the primary care level, so that only those few will get to the top in that tertiary care level, and then we'll see those dollars being spent more appropriately. But it costs our health centers—as Edna Dell said, she turned away 2,000. If the patients who visited or received



care could pay for their services, she could take that money and pay for the other 2,000 patients that she's turning away.

So, I think the answer is health coverage for all American citizens, if possible, but I think a good place to begin is certainly with the working people.

The CHAIRMAN. Do you see any distinction between the larger employer and the smaller employer in terms of the coverage? I mean are you liable to get people in your primary care that have more comprehensive kinds of coverage? Or are you seeing people with little or no coverage or those with high deductibles.

Ms. WEINEL. That's right. We probably are not drawing from the large employers because many of them have gone into insurance programs that either send or give the employees a choice of going to an HMO, or they have a panel—they've gotten into the panel kind of insurance which is much more cost contained, the insurance companies feel. My sense is that we are not drawing large employer—

The CHAIRMAN. OK. Yes.

Ms. WEINEL. Employees.

The CHAIRMAN. Do you have some impressions about the HMOs, Ms. Kerr.

Ms. KERR. The HMOs do provide services for some companies that probably would not have health insurance coverage and I think that's a plus. I think it's a step before discontinuing coverage or having the patient on the employee-subsidize coverage. So, for that reason, I'm certainly supportive of the HMOs.

But I would like to speak to the individuals coming from the large corporations. For the most part, those individuals will seek the private providers for care and they do come to us as an alternative when the deductible is very high and they can't pay them, so they end up with us. We hear our patients in the waiting room, and Edna Dell and I have laughed about this at times. You can always tell when some of the patients have used private providers before because they sit in our waiting rooms and they tell the other patients, "We used to have a real doctor. We used to go here, there and elsewhere." So they see the health center as being—

The CHAIRMAN. A real doctor.

Ms. KERR [continuing]. Little less than the real doctor. But I think over time, they get educated and they learn that we do have real doctors there, too.

The CHAIRMAN. I should say.

Ms. WEINEL. Just one more comment about HMOs. Again, one has to look at how the HMO is set up. If this is set up with a certain bottom line, the whole idea then is to see how few visits a patient can make to the HMO to meet the bottom line. I think it's difficult to make a blanket statement on HMOs because some are set up with the real idea of an HMO of prevention, and education, and some of the social services, and the mental health services, and like that, where others certainly are not. They are really set up to meet a bottom line.

The CHAIRMAN. Just a couple more questions. One is how significant would it be for you to be able to participate in a regional pool in which you could get the advantages that larger plans have to offer to—to deal with those that—I'm talking now in terms of the



coverage of your own employees; would that make much of a difference?

Ms. WEINEL. It would make a very big difference because of our inability to get many bids on health insurance at all being a not-for-profit agency. That would give us a big boom because we get by without options—if somebody gives us a 52 percent increase, we just about have to take it on the chin because there's nobody in the wings waiting to give us a better bid to come over to their company.

Ms. KERR. We are required to have Workmen's Compensation coverage, and this State does provide a pool for insurers, so that's one example that it can work. We would be happy to participate in a regional pool for providing health insurance for our employees.

The CHAIRMAN. Very good. We want to thank both of you very, very much. This has been enormously helpful insight in terms of your ability to provide services amidst the increasing pressures.

As people who have been involved in this for a long period of time. Is it your sense that it's going to get more difficult and you're going to have to turn away more people?

Ms. KERR. I would agree with that.

The CHAIRMAN. Yes. All the indices in terms of the health care system are pointing in an enormously dangerous direction. I mean we're continuing to see an increasing number of people who have no coverage. We're going to see companies that do have coverage are cutting back, and that's going to increase the greater risk. We're going to continue to see the escalation of costs for a variety of reasons that have just been touched on here.

We didn't get into some of the problems of long-term care. We addressed some of those issues yesterday as part of this health problem. We're really talking about working families here today—those that do have coverage, those that don't have coverage, the gaps which exist for working families that get caught and the enormous increase in the deductibles. The \$700 deductible is something I have never heard about until today. We used to talk about \$100 deductible 20 years ago when we were trying to get national health insurance. We're seeing all of these forces and factors that are squeezing our population including the fact that we're still 18th in the world in terms of infant mortality. We're not dealing with these issues. In terms of expectant mothers, 600,000 expectant mothers a year have no insurance whatsoever. We have 390,000 expectant mothers that have had some contact with substance abuse with all the implications that that has in terms of human experience, let alone the medical repercussions. Expensive hospital beds are being used because of the lack of nursing home care which could be a fraction of the cost. Or home care which could treat our elderly a great deal more humanely. We've got a full challenge ahead.

But our focus today was on the working families of St. Louis—the industrial heartland. There is a very strong and powerful work ethic here. This is a reflection about how our country is treating our workers especially in view of the excellence of medical facilities here. Every single community has got these kinds of problems. The witnesses who testified earlier about their enormous devotion and love of family and their loved ones is an inspiration to me and to all Americans. As the Congressman pointed out, it is a real responsibility for all of us to try and deal with this issue. And I think you've heard both from the Congressman and myself, we are fully committed to doing something about it.

We're grateful to Reverend David Roseman who's the pastor of the Maplewood Baptist Church for making these facilities available.

Congressman, do you want to say any final words here?

Congressman CLAY. No, I have no statement other than to again thank you and all of those present today.

The CHAIRMAN. We very much appreciate all of your attendance and patience. I'll tell you, in the 10 minutes we have left, if there are any individuals that would like to make a brief comment, please do so. Why don't you just line up over here.

We're going to divide whatever time we have by the number of people. I think both the Congressman and I can handle that mathematical problem. [Laughter.]

We'll try and give each person a minute. We'd like to give you longer. And for those that we cannot reach, we'll leave a member of the staff behind here with a pad, and we'll try and address some of those problems after the hearing. OK?

Try to follow the time limitations because we have others that would like to say a brief word, too, so we ask you to respect them.

Dr. JOHNSON. Good morning, Senator Kennedy and Congressman Clay. I'm Dr. Denise Johnson, the medical director at St. Louis Comprehensive Health Center, another community health center.

My concern as a physician is that, in addition to this, the physicians caring for patients who have poor insurance makes it tremendously difficult for us to provide the quality of care that our patients do deserve, and I agree with your bill. We definitely need to have better insurance for our patients so that we can continue to provide quality care.

The CHAIRMAN. Very good. Thank you.

Sister DIEPETRO. My name is Sister Mary Diepetro. I'm from the SSM Health Care System sponsored by the Franciscan Sisters of Mary.

Very briefly what this hearing has suggested to me that, in addition to the question of examining the provision for health care, perhaps the insurance industry needs to be examined.

The CHAIRMAN. Hear. Hear.

Ms. FLETCHER. Good morning. My name is Pamela Fletcher. I'm a community health nurse with the Ranken Neighborhood Health Center, and I'm cochairman of the Health Care as a Human Right Coalition.

I'd just like to point out the high infant mortality rates that we're dealing with in St. Louis, and the fact that by July, the Federally funded neighborhood health centers will be down to two OB-GYN practitioners, and this is a tragedy for our city and our Nation. Thank you.

The CHAIRMAN. Nancy.

Ms. GLAZER. Senator, I'd have given you my testimony earlier, but I couldn't stand here and do this before.

I just wanted to say I've been epileptic for the last 24 years. And there is a misconception about people who have epilepsy, I'm sure, as other diseases, too. But I think a lot of the problem is with the education of the public in the whole situation. Thank you.

The CHAIRMAN. Good.

Ms. BYNUM. Good morning. My name is Eddie Mae Bynum and I'm from South Side Welfare Rights.

And I just wanted to elude to the AFDC mothers who go to work and lose their benefits. Just making \$3.35 an hour, a mother of two

will lose their Medicaid coverage and they will be totally out of business. If the children get sick that caused the (inaudible). And again, thank you very much.

The CHAIRMAN. Very fine. All right.

Ms. KERR. Senator Kennedy and Congressman Clay, I would like to say to the group—to the audience that we will be celebrating 25 years of community health center legislation. And the Senator and the Congressman have been very diligently supporting us up in Washington, and keeping that bill alive, and keeping the health centers around serving six million individuals across the Nation. Thank you.

The CHAIRMAN. That's a good point. These neighborhood health centers were considered one of those liberal programs of the 1960s that everybody always dismissed. We made a lot of mistakes, Lord only knows during that period of time, but one of the ones we didn't make a mistake on is developing neighborhood health centers.

Thank you all for your courtesies. Thank you for your attention. The ball is in our court, so to speak, but we're going to need your help. And we're going to want you to continue to be interested and active in this program. We'll do the best we can, but we want you to stand behind us every step of the way. Thank you very much.

We'll stand at recess.

[Whereupon, at 11:40 a.m., the committee adjourned, subject to the call of the Chair.]



# HEALTH CARE CRISIS IN RURAL AMERICA

---

THURSDAY, DECEMBER 14, 1989

U.S. SENATE,  
COMMITTEE ON LABOR AND HUMAN RESOURCES,  
*Sparta, GA.*

The committee met, pursuant to notice, at 10:35 a.m., in the Hancock County Library, 403 East Broad Street, Sparta, GA, Senator Edward M. Kennedy (chairman of the committee) presiding.

Present: Senator Kennedy and Congressman Roy J. Rowland.

Mr. ROWLAND. If I could have your attention. We would like to start this hearing now that we are so fortunate to have here in middle Georgia.

Mr. Chairman, it is a real pleasure for me to have the opportunity to welcome you and your staff to middle Georgia on this cold December day. I can tell you that the weather is much colder here today than it usually is, but I am sure you are acclimated to it quite well, being from Massachusetts.

I also want to welcome you to the Eighth Congressional District of Georgia, which extends from Greene County just to the north, 270 miles to the Georgia-Florida line on the south. It is largely a rural area and we do have many problems in our rural areas now, and particularly in our health care delivery system.

We have problems such as our high infant mortality rate. We have a shortage of physicians and health care personnel in the rural areas and in our country and particularly here. The financial insecurity of our rural hospitals is a constant problem with us that has come about in many respects because of the inequity in the way that rural hospitals have been reimbursed, the large proportion of Medicare patients that they treat, the number of uninsured people that we have, the drug problem which we have already talked about briefly and the sexually transmitted disease increase which is almost unbelievable that it is so closely related to that, and the liability crisis that we have.

So while we have been trying to address some of these problems in Congress, let me commend you for the leadership role that you have taken in helping to address those problems. We have certainly made great strides in dealing with that, but we still have so many problems that we need to address, and we are just so pleased that you are here today to focus on some of those problems.

The State of Georgia and rural communities are working real hard, and I think that Sparta and Hancock County is a perfect example of how rural communities are working so hard to be sure that we have good health care and ensure good quality of life in our rural areas. After all, we see so many people moving to the



urban areas and we believe that the quality of life is much better in the rural areas in so many respects.

So we are really pleased to have you here today, Senator, you and the members of your staff, to focus on these problems. And let me say on behalf of all of the people that are here today from Sparta, Hancock County and middle Georgia, thank you very much for coming.

#### OPENING STATEMENT OF SENATOR KENNEDY

The CHAIRMAN. Thank you.

Thank you very much, Congressman Rowland. Let me say what a real pleasure it is for me to have the chance of being here in central Georgia, in Sparta, in Hancock County. I want to acknowledge what I know all of the members of the Eighth Congressional District already know, and that is how much we rely upon your insight on a wide range of issues, but particularly on the issues of health care and very specially about the challenges which your constituents have in rural parts of central Georgia in receiving good quality health care at a price that they can afford to pay.

I think all of us in Congress acknowledge the work that you have already done in the areas of infant mortality, particularly the problems that we are facing in terms of infant mortality in rural areas. You worked with former Senator Chiles on the Infant Mortality Commission, you continue to devote an enormous amount of your time and energy in that area. I know that you feel, as I do, that the fact that the United States is 18th in the world in terms of infant mortality rate is not acceptable. And I can say here in Sparta, GA that if we listened more closely to your guidance and advice not only on that issue but many others involving health care, we would be a healthier and happier country.

So I am very grateful to you for your hospitality, and to the help and assistance that you have given to me in preparing for this particular hearing.

I want to thank the mayor very much for her welcome and her kindness, her generosity in helping to prepare for our hearing. We know that you have a distinguished representative and a former mayor as a member of your family. You know, I come from a family that is involved in politics. I believe that when you have members of the family that stay in politics, that is good. We see that that is being done here in Sparta, GA and we are looking forward to perhaps hearing some insights later on after we go through the formal aspects of the hearing, we are very grateful to you.

And I want to thank all of those here that have been involved in the preparation for this hearing: Juanita Williams, the librarian; and Karen Meeks, for letting us use this excellent new facility for our hearing. I understand it was just dedicated 3 months ago and it really demonstrates the interest of the citizens of this community and the importance of education in making available these kinds of library facilities to the fellow citizens. The emphasis and stress that so many in this room have placed upon health care and their willingness to take on that issue, is a very clear indication of the priorities of people here, place on caring for their fellow citizens,

and in providing education for the young. I think it is a real tribute to all of those who are here and to many others who are not here, about your own priorities.

Hancock County was named after John Hancock who hails from Massachusetts, I am not sure at this time that I am prepared to say that Mr. Hancock was a Democrat or a Republican, but that does not matter at all, we embrace his memory and we are proud of his association with the founding of this great republic. Coming many miles from where I am at home, the fact that he made useful contributions in the fashioning and the shaping of our Nation is something that I had to mention.

And then I also know that there was a daughter of Ireland, Flannery O'Connor, who lived down the road here, one of the distinguished writers. She brought a little bit of Ireland with her over to this part of the world. So I feel very much at home here in Sparta with you, Congressman, and with all of those who share some common views and vision for our country.

I would just like to make a very brief opening comment because we come here really to listen to those that we will hear from shortly and who have a very important message to tell, and then a second panel of providers, and then to the extent that we have time left, we will hope that we might allow some of those in our audience to make some brief comments.

But this is really the last stop of a 4-day tour of the country which brought us to different areas of the country and I would like to just say a brief word about what this whole hearing really in about—as the chairman of the Labor and Human Resources Committee that has some responsibility to help fashion and shape health policy.

I believe that health care should be a basic right for all, not just an expensive privilege for the few. My family has been fortunate in being able to obtain the best of health care and it ought to be available to every family. But today we face a crisis in the health care system that threatens the well-being of every American family in communities across the Nation. Health care is the fastest growing failing business in America. The challenge is more serious than at any time since the enactment of the Medicare Act in 1965. As I have traveled across the country this week, I have learned that no one is immune from this crisis. Young or old, rich or poor, insured or uninsured.

Nevertheless, because disproportionate numbers of rural Americans are uninsured, elderly or poor, they are especially hard hit by the crisis. Right here in Georgia there are almost a million men, women and children with no health insurance at all. The elderly comprise 12 percent of the Nation's total population, but 25 percent of the rural population. So the need to deal with the problem of long-term care is especially urgent. The poverty rate is 13 percent of the Nation as a whole, but it is 17 percent in rural America. Yet, only a quarter of the rural poor qualify for Medicaid compared to nearly half of the inner-city.

When it comes to health care for the poor in this rich Nation, we have a double standard within a double standard. It is hard enough for anyone who lives in poverty to obtain decent health care, it

should not be twice as hard for those who live in urgent need in rural America to qualify for Medicaid.

Statistics tell us that nearly three-fourths of the medically under-served areas are rural, but statistics cannot tell us what it means to Sparta and its community health center to be without a physician for several months. Statistics also tell us that there is a severe shortage of obstetrical services in rural areas and that infant mortality rates are highest in the rural southeast, they reach as high as three times the national average. But statistics do not begin to measure the human tragedies that occur every day in rural counties because of inadequate prenatal and obstetric care.

What do we say to the young woman from this area who lost her baby after a premature delivery during an hour-long ride to the hospital? Do we simply apologize for the fact that the quality of health care to the poor is so poor, or do we finally begin to learn from the tragedies and resolve that they shall not happen again?

If there is one issue that should unite communities across America, it is the need to respond to these health care challenges that threaten the health of every American. Sparta responded to that challenge by floating a bond issue to reopen their county hospital a few blocks from the library. Last year the county devoted one-third of its budget to keeping that hospital functioning. The people of Sparta know that health care is important and the American people know it too.

I think that next year can be the year in which comprehensive reform of our health care system can finally be enacted, and I look forward to the views of the witnesses we will hear from today.

We want to welcome our witnesses. Our first witness is Joan Baity, and we thank you very much for being with us. Joan lives 20 miles from Sparta in Washington County, in Sandersville, GA. Then we will have Ms. Debra Brown of Greensboro and then we will hear from Mr. Joseph Sheppard of Sparta, GA. Perhaps we will hear from all of them and then we might go into some questions. Joan, we would be delighted to hear from you.

#### STATEMENT OF JOAN BAITY, SANDERSVILLE, GA

Ms. BAITY. Thank you, Senator Kennedy and Congressman Rowland. Good morning, ladies and gentlemen.

I am here to speak on my priority, Alzheimer's disease.

The CHAIRMAN. If you would be good enough to hold for just a moment. I want to point out, I think all of us are very mindful that it is always difficult to talk about our health care needs. I think most Americans, all of us, frankly would rather not speak about the health challenges that we face individually, personally, or those of a member of the family. We have some of those today that are willing to share these life experiences with us and I think the challenge then for the Congressman and myself is to really do something about it.

So I am very mindful at the outset that these are never easy stories to tell, they are very personal stories to tell, and we are very grateful to our witnesses for being willing to share those with us here this morning and we will share the stories with our colleagues



in the Senate and try and address some of the challenges which those stories present.

Joan, I hope you have the mike in front of you now so that we will all have a good chance to hear you.

Ms. BAITY. Let me repeat again, I am here on behalf of my mother who is an Alzheimer's victim. I appreciate the Senator and the Congressman's time to be here also.

We were raised in Illinois in a farming community and came to Georgia in the Fifties. My mother and dad both have worked in the cattle industry and been hard workers all their lives, never being in the higher income brackets and now living on Social Security.

My father died in February with cancer and in the meantime my husband divorced me due to the strain of both illnesses. My mother at that time was able to take care of him, we did not know that she had the early onset symptoms of Alzheimer's disease.

Until it hits your family, you are not all that concerned with something so devastating as to take a bright and beautiful woman, outgoing and loving and caring, and she is now bed-ridden, unable to speak in more than just a "yes" or "no" and a few sentences, totally incontinent, angry and hurt at times with people coming in and out of her room. She responds at whatever level she is for that day and it is never the same, every day is different. It is hard to work with someone who is hurt in the mind, the alienation of your own family, people who will not come around you because they feel like mother is going insane, or as I have a brother who says my mother died 2 years ago. That is hard to accept.

Let me give you just a brief history of what has happened to me, and I realize this is not the norm, this is just some things that have happened to me in the 3 years that I have watched my mother become almost a child again.

I left here in 1980 and moved to South Carolina to be married and I worked in the court system there. I came home every few weeks and noticed just slightly that mother was changing, personality disorder, confusion and forgetfulness is the first thing that you have happen. But you do not recognize that, you think that is senility, you just sort of pass it off and keep going.

Well daddy had surgery for cancer in 1986 and recovered. Mother was able to take care of him for awhile. She could do light housekeeping, maybe hang the clothes out and a little cooking, but all that changed, because she used to do everything.

Then she broke her hip in June of 1986 and when she came home there was a total change in personality. I had to leave my job and leave my husband on Mondays and come down and stay until Friday and go back. The strain became more and more and he divorced me in 1987.

Mother had to have intensive care, as far as physical therapy for her hip, and by October she broke the other hip. By that time she was going into rages that no one understood, no one knew how to deal with, day-to-day three and four loads of clothes to be washed, and the drain mentally and emotionally is devastating. You cannot imagine until it has happened to you.

My father became ill again with cancer and over the 7 months that I kept him at home and my mother, he was going downhill. We already knew it was terminal but it happened a little quicker



than the doctors said. They gave him 6 months to a year. She could not take care of him and at this point she is not aware that he has died. There was no way we could tell her and make her understand that.

She went through a period that she could still read and write, she could still walk, sometimes she was violent, she might throw the walker at you, she might hit you, she has knocked me down. She has kept me bruised and beaten, besides the mental factor.

But I cannot tell any of you how hard that is for anybody who has to go through that. And according to all that I can read, and I know more about Alzheimer's than any of you will ever want to know, there are at least four million people in these United States with it. It is projected to the year 2050 there may be 14 million.

There is very little help for my mother. We live on her Social Security. She is in, you might say, perfect health except for that but she is bed-ridden now and I need some help. Some way, some how, I need some help.

I do not know what else we can do for her at this point, but with the family alienation and the caregivers across this Nation, for everyone who is out taking care of a parent, you have effectively taken two people out of the work force, and as Congressman Rowland and Senator Kennedy have alluded to the fact that we have drugs and everything else, when you add health care to that, the work force is dwindling and we need some sort of help.

Senator Kennedy, I appreciate your work on the Pepper Commission, and if you could take a message back to all of your constituents there and also your colleagues that we need help. We appreciate all you have done so far, and I wish you God-speed in your endeavor.

The CHAIRMAN. Thank you very much. That is a very powerful message of love. Obviously your attention to your parents at the time they are facing extraordinary challenges; your father and now your mother, is really a lesson of inspiration about what the whole teachings are about. So I would hope that with the enormous challenges that you are dealing with, we know that there are many people that you inspire.

You have inspired me today and I am sure those that listened to your story. So I think you ought to know that right at the start.

Let me just ask a few questions.

Did you have any insurance to help you and assist you during this period of time?

Ms. BAITY. My father went through a period of having someone come in and bathe my mother before I came there.

The CHAIRMAN. I was asking just about insurance. Then I want to ask you, you know, about what kind of help you might have received. But did you get any—were you covered at all?

Ms. BAITY. She had insurance but he had to put her on one of the Medicaid programs in order to have the help but now we cannot get any more.

The CHAIRMAN. OK.

Ms. BAITY. We not only cannot get it because of her age and her disability, but nursing homes reject her also. Most nursing homes will not take an Alzheimer's victim because of the violence and incontinence.

The CHAIRMAN. So if you had the resources, you would not be able to place her in a nursing home?

Ms. BAITY. No.

The CHAIRMAN. Now have you been able to get any help and assistance to try and relieve you from what I imagine is almost a 24-hour responsibility.

Ms. BAITY. Yes, sir, it is. There are two family members that come long enough for me to go to the grocery store and go to church, but as far as having someone else come, you have to pay out of pocket for that.

The CHAIRMAN. You get no help or assistance on that, you have to pay out of your pocket?

Ms. BAITY. That is right.

The CHAIRMAN. And that effectively comes out of the Social Security?

Ms. BAITY. Yes, it does.

The CHAIRMAN. Let me ask you as someone who has been coping with these dual kind of challenges for some period of time, what would make the most difference to you in terms of caring for your mother? As you mentioned, you are a real expert on this, perhaps out of tragic circumstances certainly, but what would make the most difference to you?

Ms. BAITY. An afternoon a week, just an afternoon a week.

The CHAIRMAN. That is not asking for much. You mean having someone who might be able to come in and deal with her, skilled care?

Ms. BAITY. It would have to be semi-skilled at least.

The CHAIRMAN. Semi-skilled and have some understanding perhaps of the mood swings with Alzheimer's, etc.

Ms. BAITY. Yes. Someone would have to be able to tolerate the violence.

The CHAIRMAN. But people like you are willing to try and come to grips with this kind of situation. You are not asking for much, just an afternoon a week. You would think our society would be able to shape or fashion that kind of a program.

Congressman, do you have questions?

Mr. ROWLAND. Thank you, Senator Kennedy, and, Joan, let me thank you also for that very moving statement that you have made.

You focused on one area that perhaps we tend to forget about, and that is the strain that is placed on the family and what an illness like this can do to an entire family. You talked about the fact that two people are taken out of the work force in order to meet the needs of the individual that is sick.

I appreciate you focusing on that because that is such an important aspect of overall health care.

Ms. BAITY. Definitely.

Mr. ROWLAND. And that is one of the things the Congress is struggling with now and has not been able to come up with a solution to long-term care, to help address the very problem that you mentioned. You also mentioned the depletion of resources and becoming eligible for Medicaid because of that. It is so distressing for people like Senator Kennedy and myself in the Congress to try to deal with these problems too.

He has already asked you about what would be the one thing that you would really like to see happen and you said an afternoon a week. I think that illustrates that so many people want to keep their families at home. They do not want to see them leave home, and they just need some help.

Would you say that is one of the principal things?

Ms. BARRY. In our family it is, we focus on family, my church focuses on family and to be able to keep her at home so that everyone could see her, those that wish to, would be the best thing we could do. When she was ambulatory, I could take her for a ride and come back to the house and she would say why are we stopping here, she did not recognize her own home. Being with family she still smiles when someone walks in the room. If you touch her hand or touch her head or stroke her hair, she still smiles. In a few minutes she might decide she wants to punch you out, but when they are ambulatory, adult day care would help, but help of any kind would help just to get you back on your feet and keep you going.

The CHAIRMAN. The health challenges—just in conclusion—that you are facing are monumental challenges, but here we have a fellow citizen of our country who wants to work, had a job offer, would work, has a life experience of working in our society and only because of love of mother and father, the basic and fundamental values of our society, is put into this kind of condition where she has to see effectively the family bankrupted before we, as a society, will reach out and try and provide some kind of minimum standards, and then have to, out of that kind of love and caring, take care of a family member, and be willing to do that and then comes here noncomplaining. The only thing she is asking for is to have the time to be able to go to the grocery and go to church and maybe have an afternoon a week.

Now if we cannot try and deal with that kind of an issue and problem as a society and do it in a way that is fair and just, we have to really ask about our whole sense of humanity and decency as a society—we just have to. If that does not ring out—I mean who among us would change places and cope with this kind of situation. If we, as a society and a community are better off because people such as Joan are willing to take care of a chronically ill family member, what is it that restrains us from trying to deal with that particular challenge and offering these people some relief?

Well, as I say, we are enormously appreciative.

We will hear from Debra Brown. Debra, we are glad to have you here and we appreciate very much you joining with us as well.

#### STATEMENT OF DEBRA BROWN, GREENSBORO, GA

Ms. BROWN. Good morning, Senator Kennedy and Congressman Rowland. I thank you for this time to talk to you about the concerns I have about my 7-year-old daughter Shondell which has a chronic illness.

I am a divorced parent with three children and limited resources. I am having more and more worries about getting the kind of health insurance I need to protect my family, but particularly my



daughter, Shondell, who is sitting in the front row. Shondell is the youngest of my three children. Ever since she was a very little girl, she has suffered from acute asthma. Although Shondell is normally very active and happy, her serious respiratory illness can make her very tired and listless. Several times her problem has been so severe that she had to be hospitalized.

When she was only 2 years old, Shondell had to be put in the hospital. She had one of the worst attacks that she had ever experienced. She was hospitalized for almost 2 weeks, she was in intensive care. At that time, we were fortunate because my husband and I were both working and had coverage that paid most of the cost of Shondell's care.

I have always tried very hard to keep insurance coverage that would protect Shondell but I have had more and more problems recently. Over the last 3 years I have had different jobs but each job I was covered by different insurance companies. When it comes to coverage for my daughter under these plans, all these companies told me the same story, the company had exclusion for certain chronic conditions. Sometimes they would not cover treatment for asthma at all, other times they said coverage would not start until I had been a policyholder for at least 2 years. So I found it hard to see what kind of protection the insurance was giving my daughter.

A little over a year ago I had to carry Shondell to the hospital even though I knew my insurance policy would not cover the cost. Luckily my ex-husband came up with more than \$4,000 to pay the bill. However, he no longer provides any support. I do not want Shondell's health to depend on whether or not he wants to help out.

Last month I was laid off and now I have no health insurance for myself either. The people at the plant gave me the chance to continue my health insurance policy, but my income is so low that I cannot afford the increased policy cost.

Of course I am worried about not having health insurance for myself, but I am more concerned about Shondell with her chronic illness.

As I look for work, I am trying to be sure to find a company that has an insurance plan that would cover my family, especially Shondell. Until I get another job and find some other means to get health coverage, I will remain worried about not having protection in case my daughter needs treatment. I am worried that I will hear the same message again, that her condition will not be covered or will require a long waiting period.

This situation is very unsettling for a mother who is worried about her child's welfare. I have looked into Medicaid coverage but I was told that my income makes me ineligible.

I know that all of you who are parents understand how painful it would be to see your child gasping or wheezing to get the next breath. When this happens to my daughter, I want to be able to carry her to a doctor right away. But since she is not covered, I do not know what I face if Shondell has another serious attack. There are so many things that can make Shondell have terrible breathing, it is hard to try to keep her away from all of them. Also, it is hard to try to restrict activities of a 7-year-old who wants to get into everything. I just do the best that I can and hope that Shon-



dell does not get sick. And it is so painful to see a child suffer when you do not know whether or not when you take that child to the hospital that they are going to turn you away just because you do not have the adequate means to provide for that child.

There are so many more Shondells around, you would just be overwhelmed. I believe that there is some way that we can be helped because if your idea was in doing the best that you can and that is not enough, there should be some way, some provision that we can get some type of assistance.

I thank you very much for your time.

The CHAIRMAN. Well thank you very much, Debra Brown. I think we see the first witness, obviously the child, member of the family, caring for their parents and now the love of a parent for a child. Here we have someone that is working, wants to work and is put to the first interest, their whole life, being able to get an insurance policy so they can have coverage for their children, moving from job to job and finding out that even when you have those insurance policies, you have those exclusions, "This policy works with the exception of . . .," and that is always what you need—generally.

We see that in terms of births, excluding problems that come within the first 10 days of a birth, which eliminates about 90 percent of the complications in terms of infant birth. Here we have in regards to the chronic diseases and in this case, asthma. I am certainly very empathetic and sympathetic with Debra Brown because I have a son, Patrick, who is a chronic asthmatic. I have made that same trip and you just never know when that child is fighting for breath whether that is going to be the last breath—you just do not know it. And you have difficulty in understanding how anyone can have that much difficulty in breathing and survive. And you complicate that with wondering whether you are going to be able to get in there and get treatment, what that does to you as a parent in our society. It is just really unrealistic.

And I am sure, Debra, you probably wonder about the things that are going to set your child off. I remember being up in Boston and being outdoors and having a dog come around and sniff my ankles and flying back to Washington, going into my room, changing my clothes, my son coming back in, and 45 minutes later having to take him down to the hospital because of the fibers that came from that suit were in that room, and having no understanding of what set him off. Facing that every single day and not having the other kinds of protections, having that anxiety. And he is lucky, but at age 22 he has not grown out of it, you always hope that people will grow out of it. President Kennedy had asthma, he had problems visiting, traveling and going to different people's homes, he would go in and take a nap and come out and his eyes would all be filled up because there had been a cat or something on that bed, 5 hours before. He was able—that is not the kind that you described here, but this is something.

Could we introduce your daughter? Is that all right? Would she stand up over here? Shondell, could you just stand up? We just want to get a look at you. We want to thank you very much, we saw you looking through a little book over there. We are very glad to have you here. We thank you very much for joining with us and

we very much appreciate your mother being here. We hope you will say hello to the rest of your family for us.

Thank you very much. [Applause.]

The CHAIRMAN. Let me ask just a couple of quick questions. Does the fact that you live in a rural area, does this make it somewhat more complicated or difficult the longer time it takes you to get to a medical setting?

Ms. BROWN. It does, because she has to have special care and facilities at our local hospital, it is not equipped to handle all of them, so I have to commute at least 35 to 40 miles in order to take her to get the adequate care that she really needs.

The CHAIRMAN. And do you have to make special arrangements in case you have an acute episode?

Ms. BROWN. Well yes, I have to make sure that she has her medication before she leaves home, I have to carry her medication over to the school and give them instructions as to what to do. And when I am working, I have to make special provisions so that my mother can go and pick her up and take her home and they will not have to wait on me in the event that she does have an attack and I cannot get away just then.

There are a lot of different things that you have to deal with when you have a child with such a problem.

The CHAIRMAN. Let me ask you, you did not talk about those prescription drugs, but they run up a little bit.

Ms. BROWN. Yes, they are pretty costly and you have to have them on a regular basis. She has to have medicine every day.

The CHAIRMAN. And they can run up.

Ms. BROWN. They are not cheap at all.

The CHAIRMAN. I think I hear you.

Ms. BROWN. In fact, one prescription that she has to have is like \$72 per bottle. She has another one that is 35 and she has to go periodically and get shots. Those range anywhere from \$35 a visit to \$40 or \$45 a visit.

The CHAIRMAN. Thank you. Congressman Rowland.

Mr. ROWLAND. Thank you, Senator.

I suppose one of the most frightening things that can happen to a parent is to see their child with asthma. I have seen this on many occasions in the emergency rooms and if it develops into a condition called status asthmaticus it is truly life threatening. I want to thank you for the testimony that you have given. Let me also thank you for focusing on one area and that is the 31 to 37 million uninsured people in our country. When we talk about our health care delivery system, so many times we do not focus on those people that do not have insurance. Senator Kennedy has already mentioned that we need to look at some fundamental changes in our health care delivery system, and certainly I think that we do. And we need to look at the problems that you have so clearly illustrated to us here this morning, in not having insurance.

Let me ask you this question. Because you do not have insurance and because you may not have the money to pay for a visit, are you ever reluctant to go for care because of that? Does that stand in your way at times?

Ms. BROWN. Well at times I am sort of hesitant about going, but then when I know that I really have to go, I go and I just try my luck.

Mr. ROWLAND. When you say you really have to go, that is you get to the point that you are afraid something bad is really going to happen.

Ms. BROWN. Right.

Mr. ROWLAND. You might put off going—it could have been dealt with more easily but because you might wait it causes the problem to become more severe.

Ms. BROWN. This is true.

Mr. ROWLAND. I think we see that so many times, Senator, if people would go early, it would certainly be much less expensive and much less stressful for everyone if that could take place.

Thank you very much for your testimony.

The CHAIRMAN. As the doctor is pointing out, people have to wonder whether they are \$75 or \$100 sick. That is what the emergency rooms are in part of the country, and they have to wait and wonder, and meanwhile they go through that kind of anxiety that Dr. Rowland—Congressman Rowland talked about, wondering whether that child—to have to put anyone through that, both sick person and parent, is something that we should not be involved in.

Joseph Sheppard, we are glad to have you here. And I want you to tell us just a little bit about yourself. Tell us your story.

#### STATEMENT OF JOSEPH SHEPPARD, SPARTA, GA

Mr. SHEPPARD. First of all, Senator Kennedy, I would like to welcome you to Sparta, along with Congressman Rowland.

My name is Joseph Sheppard, I was born and raised here in Hancock County, Sparta, GA. After I was married, I moved to Jacksonville, FL, for a short stay but after a death in my family in 1975, I moved back to Sparta, my wife and I. And since then I have been off and on self-employed. I worked for companies prior, but now I am a self-employed man.

This past June of 1989, I became ill. I thought I was coming down with the flu or something similar, or a cold, and I began to treat myself as such. I took some medication that was a little bit too strong for me because I am not used to taking pills, and I became dizzy and I fell down. Although I did not know it at the time, I was suffering from perirectal abscesses. By my falling, I ruptured those abscesses, bringing on severe swelling and soreness. So I went to Dr. Wendell Smith at the Primary Health Care Center the following morning. He examined me and told me I had two things; either I had prostate trouble or I had perirectal abscess and he said that I needed to go to the hospital right away.

But I explained to him that I did not have health care insurance and I asked him if he would treat me without going to the hospital. In his trying to do so, Senator Kennedy, he did the best he could with me, trying to treat me as an out-patient. But he looked at me and he told me "you need to go see another doctor." I went to see Dr. Green. When I saw Dr. Green, he looked at me and told me that I needed to go to a hospital, that I needed to get help right away. So he gave me a shot to ease my pain and sent me off in my



travel to Augusta, GA which was some 70 miles away from these facilities. There I knew they could treat my condition.

I was admitted on June 27 of 1989 and I was operated that same night, I spent 14 days in the hospital and had three operations including a colostomy. I have always been a healthy man without problems in the past. I have never been sick since I was in the 8th grade other than having the flu or a minor cold. I have never taken anything stronger than aspirin in my life for the past 30 years.

I am self-employed and I cannot afford health insurance. It is simply too expensive for one person to pay. My wife was not able to have insurance on me where she works due to the fact that the premiums, we could not afford it because she only makes the minimum wage.

Because we did not have insurance, I held off from going to the hospital even though two doctors had told me I should go. I am a proudful man and I did not want to make a bill that I could not pay out of my pocket and put me in debt for the rest of my life.

If I do a painting job for you, Senator, I expect to get paid and likewise so does the hospital if they do work for you. I do not want to ask for something I could not afford, but in this case, I was forced to it anyway, I had no alternative.

My bill as of now is approximately \$40,000. I am about halfway through my illness. I hope that all goes well for me, I go back to the hospital tomorrow, so that I may be able to remove this colostomy. Again, when I go back, I am still looking at another possible \$10,000 to \$15,000 even with the out-patient care. That, too, will be a bill I cannot pay.

I have had to depend on my friends here in Hancock County and Sparta, and I have had to depend on my relatives all the time that I have been sick. They have kept my lights on and they have kept my gas going. For a time my wife was working, but she had to quit to take care of me, because I demanded 24-hour a day care due to the situation of my operation.

Being self-employed, Senator Kennedy, is like a feast and famine situation. Your earnings are very much uncertain, you do not know from month to month as to what you are going to make. When you live in a small town like Sparta, it is hard to make a living. It is even harder to afford health care. Living like that can certainly put a person in a poor mental and physical condition. I understand these two colleagues that I am with, I know what they are going through.

If it had not been for the help and professional services of the Hancock County Primary Health Care, I probably would not be alive today. Due to my pride and my hard-headedness, not wanting to make a hospital bill, I put it off almost too late. But I eventually took the advice of Dr. Smith and Dr. Green to get myself well first and then cross that other bridge of paying that other bill when I get to it.

The services that my wife and I get at the Primary Care Center, based on our income, certainly is a great benefit to us.

Senator Kennedy, I would like to reemphasize just one point on my behalf and for millions of fellow Americans throughout this country of ours, that if it was not for the professional care center,



if we should ever lose this center's professional care, my wife and I and others that are in even worse shape than I am, financially or physically, will simply have to just stay home, suffer due to the lack of a doctor's care.

And again, Senator and Congressman Rowland, I would like to thank you for your efforts and your time that you have put forth to come to Sparta, GA and speak to me and others that are in the same situation.

Thank you.

The CHAIRMAN. Thank you very much. [Applause.]

That is why we are down here, Joseph Sheppard, to try and hear from the people in this community. We can hear a lot of witnesses up in the hearing room in Washington but I am sure the Congressman feels the same way, if you have Members of the U.S. Senate and Congress here to hear what we have heard today, you would get some real action, I am convinced. We are going to take those messages back to our colleagues.

How long have you worked—when did you start working, doing chores and that sort of thing?

Mr. SHEPPARD. Well, I have been self-employed off and on for about 15 years, but I was in the work force with other companies for about 15 years too.

The CHAIRMAN. So you have been virtually working all of your life.

Mr. SHEPPARD. Every day of my life. [Laughter.]

The CHAIRMAN. And your wife was working too?

Mr. SHEPPARD. Yes, sir.

The CHAIRMAN. Here we have two individuals working hard, self-employed, working for himself, ready to take the risk of self-employment, the good times and the bad times, the uncertainties on it, and have that kind of spirit which comes through so clearly in your presentation.

When you are self-employed or an individual going out to shop around and try to buy insurance for your family, if you can get it for \$250 or \$300 a month, you are doing pretty good. That comes to \$3,500 a year, which is virtually prohibitive in terms of working families in this country—virtually prohibitive. And I dare say if those insurance companies find out that you have had one illness, you are never going to get coverage no matter what you can pay. That pre-existing condition exclusion, that little quote, if they find out you have been down to that hospital for a couple of days, Lord only knows what they will go out and try to find out about you so that you do not get coverage for that particular illness.

I frequently have stated, that my son who had cancer at the age of 12 and survived, but lost his leg to it, can never in the United States buy insurance again in his entire life, never, because he had cancer. That is true for other families, you can look around this room and I am sure we could find other stories similar to the kinds of stories we have heard here.

We will hear some of our colleagues say, "Well, you just went down to Sparta, GA and finally found three individuals that had these problems." However, we have been listening to this across the country. Yesterday in St. Louis, we had two families, the Hancock family, and the McDaniel family who relayed similar kinds of

problems. There is not a community, large or small, in this Nation where you could not find these kinds of circumstances, not one.

We have people in our country that have virtually a non-system of health care. All of us who have been able to have the best, and I have, know it is extraordinary when it works, but there are so many of our fellow citizens who never even get a chance to get at bat with the system, to have an opportunity to benefit, because of the kinds of circumstances that we have just heard about here. And that I think is basically and fundamentally wrong. We ought to be able to deal with it.

That we can find hard-working American men and women who have worked throughout their lives and are self-reliant, self-employed and they are prohibited, virtually blocked out as certain as if that door is locked, from being involved in the system, that is wrong and we ought to try and see how that can be remedied. And this is increasing as a problem, not getting better.

I just had a couple of brief questions. As I understand it, you tried to get health insurance in the past and it was just too expensive.

Mr. SHEPPARD. Yes, sir, absolutely.

The CHAIRMAN. Were those figures roughly, a couple hundred, \$250, what they were quoting to you? Do you remember?

Mr. SHEPPARD. Near double that, yes, sir.

The CHAIRMAN. OK. Do you know, Mr. Sheppard, as we find the health care system one of the fastest failing businesses, one of the growth industries in this country are collection agencies. No end to their resourcefulness in finding out your phone number and hassling you about those few bucks that you have out there. That again says something about where we are, but we do not want to hear any more from me. I recognize Congressman Rowland.

Mr. ROWLAND. Just a comment, Senator, and Joseph, I want to thank you very much for your testimony. You have substantiated the point that I was trying to make earlier about delaying care until it is much more expensive.

I found when I was practicing medicine that there were people who would not come in, who felt that they did not have the resources to pay for that care, whether it was insurance or cash money, and then they would get much sicker and that is exactly what happened to you.

Mr. SHEPPARD. Yes, sir.

Mr. ROWLAND. You felt that—you are a proud person, as you said, and I think that is the way most people are, they do not want to infringe, or perceive it to be infringing on someone else. You certainly make an excellent point in your statement and you just confirmed what I have believed for so long. Thank you very much.

Mr. SHEPPARD. Yes, sir.

The CHAIRMAN. Mr. Sheppard, we are going to come back and have you show us how you work that painter with one arm. They say you have got a knack for doing that.

Mr. SHEPPARD. I should have.

The CHAIRMAN. We want to thank all the members of the panel. The best way we can thank you is to try to work on these problems and you have my commitment and I know Congressman Rowland's

as well. That is the best way we can say thank you. We hope you will stay for whatever time you can for the hearing.

Thank you very much.

We will go to our second and final panel and ask Dr. Ted Holloway and Mr. Gary Dollack to present their testimonies. Dr. Holloway is a third generation country doctor, director of the Southeast Health Unit of the Georgia Department of Human Resources, founder of the Daisy Clinic which provides health care for children; and Mr. Gary Dollack, who is the administrator of Hancock Memorial Hospital located in Sparta. We had a chance to go out and visit the hospital very briefly this morning, it is a splendid facility and I know the citizens are proud.

Dr. Holloway, we look forward to your testimony. I know you have a very interesting and distressing report for us. I do appreciate very much hearing from you.

#### **STATEMENT OF DR. TED HOLLOWAY, DIRECTOR, SOUTHEAST HEALTH UNIT, GEORGIA DEPARTMENT OF HUMAN RESOURCES**

Dr. HOLLOWAY. Thank you very much. I really appreciate the opportunity to be here.

Access to medical care in the rural areas has always been a problem, but I have been in south Georgia now for 15 years as Director of Public Health, Mental Health, Mental Retardation and Substance Abuse services for an area about the size of the State of Massachusetts. We have about 270,000 population, 78 percent of our Black population lives below 200 percent of poverty and about 45 percent of our white population.

The problems I have seen in the last 4 or 5 years have just overwhelmed our whole system. We have many people coming to the health departments with chronic diseases they cannot get care for, problems that we are unable to take care of in the local hospitals. We have 14 local hospitals in these 16 counties, only two or three of these hospitals have any funding at all to provide any indigent care and virtually all of the hospitals are in financial danger of going under because of changes in health care reimbursement and the differential that rural hospitals do not get as much Medicare reimbursement as urban hospitals. But there are some special populations that we find just totally left out completely.

We are kind of the home of the Vidalia onions and we get a lot of migrant farm workers in Georgia over the past few years. There is only one small migrant program in the whole State of Georgia and we have had that program to serve only four counties and we have had flat funding from the migrant program for about the last 5 years. So we have actually lost services, the few out-patient services we were able to provide and we have not been able to provide any in-patient services at all.

Another tremendous area that we find, as has already been alluded to, are the problems of the aged and the mentally ill and mentally retarded. There is virtually no residential care that is available. The new regulations are putting a tremendous burden on our local communities in looking at people who may not be in the ideal world appropriate for nursing home care, but that is actually the only care that is available, residential care that is available,



and we are looking in my area at 300 to 400 people who are chronically mentally ill being put out of nursing homes over the next year because of the OBRA regulations.

The major problems that I deal with on a day-to-day basis are maternal and child health problems and the problems of infectious diseases. And we were very proud from 1974 through 1980 to have cut our infant mortality rate almost in half. The WIC program which serves actually 60 percent of all women who give birth, 4,000 births a year, are on WIC in my 16-county area. So we cut our infant mortality rate from way above the State rate to way below the State rate working with local physicians and hospitals, but since 1980 we have gone from 52 doctors doing deliveries to 26 doctors now doing deliveries and many of those doctors are older and not sure how much time that they want to continue with the medical liability problems and the lack of funding.

The crack epidemic has just been phenomenal in south Georgia. We are right on the Florida border, we are close to the coast—I-95 and I-75 are two major interstates that come up through Florida and are drug corridors into our State. We have seen the crack epidemic go from almost no one using drugs in 1984 to where it just seems like it is everywhere now. Just last week I was talking to a policeman in one of our rural counties who said that the drug dealers have totally saturated the market of employed people in the 18- to 25-year-old group so now some of the drug dealers are doing fountain pens—taking the guts out of them and taking a piece of crack that they call a french fry, it is like a long thin piece of crack, hiding it in the fountain pen and taking it to school and selling it for a dollar. You know, they just scrape it off on a homemade pipe or a pipe they can make out of tin foil, and sell 75 cents or a dollar's worth of crack to get it down where it is affordable for lunch money.

We have had 60 percent of our cases of syphilis in the last 3 or 4 years have been in females. Prior to 1984, the most cases of syphilis we had in any one year was 60 cases and we usually ran 40, 50, or 60 cases a year. So far this 11 months, we have 451 cases of syphilis, 60 percent of these have been in females and for the first time we are following—right now we are following six children who have congenital syphilis. The last time I had seen congenital syphilis was back in 1978.

We are estimating that 5 to 10 percent of all of our prenatals in our population are using crack cocaine. Our low birth weight babies, less than 500 grams, have tripled from 1986 to 1988. We had the highest infant mortality rate last year, we had a mortality rate of 16.4 percent which is the highest that we have had since 1978.

The problem of syphilis spills over into the other epidemic that we have been in the middle of and that is the epidemic of AIDS. Many people do not think that we have got a problem in the rural areas, they do not understand this epidemic and how early we are in it, but Georgia is among the top 10 States in the country with number of cases of AIDS per 100,000 population. Our rural areas are especially hard hit. Over the next 10 years, we are going to have 10 times as many people with AIDS in the rural areas as we had all during the 1980's.



When we take syphilis, which has gone from 50 cases a year to 50 cases a month, with people who are sexually active and having 30 to 40 sexual contacts a week, we have genital ulcers, we have people actually going door-to-door selling sex and we have the ingredients for a heterosexual wave of the AIDS epidemic similar to the pattern seen in central Africa and Brazil and some of the other developing countries. And I truly believe this will be the next wave of the AIDS epidemic in the United States.

We see HIV-positive people who cannot get health care. We identify them, we talk with them, we explain to them that they need routine care and they cannot get it. So their motivation to either change their behaviors or to get into drug treatment are just not there because it is not available. In the last month, I have talked with a woman who has three children who is a crack addict who is HIV-positive. She cannot get care, her children have been taken away from her, so she is not eligible for Medicaid. She is not to the point of AIDS yet, so she cannot get on disability. So she cannot get AZT or aerosolized pentamidine unless she goes to prison, and it is ironic in Georgia that the only people who can get care for this disease are those who are in our State prisons, if they do not have any money.

Last week I held the hand of a young man who was dying in a large hospital in Atlanta, who lost his Medicaid because his disability insurance came in and it was \$50 a month, too much for him to stay on Medicaid. It was a very important \$50 a month. He died last week.

It is just absolutely incredible what is happening. Two out of every thousand of our live births in our rural area are from HIV-positive women as of last year, and a study that we are conducting right now looks like it may be up to about three and a half to four women out of every thousand live births are from HIV-positive women.

We have had, in Georgia, an expansion of the Medicaid benefits for more pregnant women and that has been a welcome step in Georgia and I hope that we can, in Georgia, move up to 185 percent of poverty. We moved up to 100 percent of poverty for pregnant women now.

But this comes at a time when the hospitals do not have OB services, they do not have care available. We have the crack epidemic and it is virtually impossible to get the care needed for these people.

So we really are in a state of crisis in the rural areas with health care that I am becoming really depressed about. I felt up until about 1984 that we were making headway with our alcohol and drug treatment programs, with our mental health centers, our mental retardation programs and our public health programs, but I feel now in almost every area that the reverses we have made—the gains we have made over the last 20 years are going to be reversed during the next decade.

We really appreciate your efforts and Congressman Rowland's efforts to do something about this. I feel there is no greater need in the United States than to provide care. I really feel that for the AIDS epidemic particularly that the compassionate response to this epidemic is to provide care and that is also the best public health

response. The quality of life is immeasurably better for people who do have access, and for people who have access to care, it has been shown conclusively that it will also change their behaviors and we will have less transmission. So I feel that the next few years are critical and I feel we are in a failing system, and I hope we do not, in this country, have to wait until 60 percent of the population is without health care before we make some major changes to provide access to everyone.

Thank you very much. [Applause.]

The CHAIRMAN. Very distressing report and obviously one that is extremely ominous in terms of the whole health care system.

What is your sense, as somebody who has had responsibility in the department for 14 or 15 years, about where this system is going to go, what you have seen in southern Georgia, in some of the counties there? Do you think it is inevitable that what you have seen is going to gradually move into other rural communities? From your own experience as someone who spends a great deal of time on these issues and has seen the evolution in terms of additional challenges, whether it is the substance abuse—what can be learned from your experience that would be helpful to us in trying to look down the road to the future?

Dr. HOLLOWAY. We have seen the syphilis epidemic start in south Georgia and it has now moved up the State and as the crack trade has organized, it is really coming into all areas. The Macon area now is experiencing a major syphilis epidemic just this last year. So I have no doubt that this is going to spread nationwide and the crack trade is just so insidious that it just overwhelms our whole system. We do not have treatment beds, we do not even have counselors within our own system who are familiar with how to treat people who are crack abusers. We have had people who were using alcohol or powdered cocaine for 8 to 10 years who within 6 months of getting on crack just hit the bottom.

So I am afraid that it is going to keep going. I really feel like we have got to have certainly the law enforcement and the prison space for people who are dealing, but we have got to have treatment capacity for people who are users and victims of the system.

And I believe that in Georgia, with the public and private medicine combination, we can provide care, say for pregnant women, who are on crack if we were allowed to co-manage the patients on Medicaid. Right now if they are on Medicaid, the health departments cannot be reimbursed, but the private doctor will. But we have all the coordinated care resources to go out and find women and try to get them—women who are not motivated, to seek care for themselves, so I really feel like we have got to have some public-private joining of health care.

The CHAIRMAN. Let me ask you about another area and that is teenage pregnancy. How much of that are you seeing? Is this a problem?

Dr. HOLLOWAY. It is a tremendous problem in all of rural Georgia. In our area, 20 percent of White infants are born to teenage mothers and 33 percent of Black infants are born to teenage mothers. And now with crack, we are seeing a different group of people. A few years ago we did a survey among our teenagers who were pregnant and actually 85 percent of the teenagers that we inter-

viewed desired that pregnancy. I really believe we are seeing kind of a different group of women getting pregnant now. We have made a lot of in-roads with education in schools and there has been a change of attitude among some of the teens, but now we are seeing people who are getting pregnant secondary to their crack use the same way they are getting syphilis or they are getting HIV infections. There was not a desire to be pregnant, so there is even less caring for the child than we saw in past years.

The CHAIRMAN. With all the attendant problems of child abuse, over-burdening of the support systems in terms of child care, you are finding, as I understand it, in Florida that in terms of addictive babies, hospitals in California alone are spending an additional \$500 million to \$1 billion a year to care for the stricken infants of drug-dependent mothers. Society has got to deal, as you point out, with the supply side, with interdiction and certainly the law enforcement but we are going to have to deal with the demand side as well. No one is minimizing the complexity and the difficulty that we have, but we are going to have to start dealing with the demand. You can try to cope with what is happening down at the end of your mountains but if they are able to produce what they call this ice in laboratories here which is as devastating, as I understand, as crack, we are going to have to really come to grips with what is happening in our society, its problems and challenges, in a responsible way.

Just a final question. Is there an association that you are a part of, that you are exchanging information? I understand these problems are probably coming out of Florida, I never knew that northern Florida had these kinds of problems. But is this happening in other parts of the southwest or maybe even in areas in the northeast where you have entry levels and we have rural areas up there as well?

Dr. HOLLOWAY. We are beginning to see these problems. It was interesting at the International AIDS Conference in Montreal, there were only a couple of papers that talked about the relationship of crack cocaine. There were only about three papers presented out of 6,000 that dealt with crack. But now it is more and more being recognized, the sexual transmission of all these diseases. CDC is now recognizing more and more of these problems from Washington State to south Georgia, so I feel there is a growing awareness of the magnitude.

The CHAIRMAN. Congressman Rowland.

Mr. ROWLAND. Thank you very much.

There is something I want to ask your opinion about, Dr. Holloway, which I think is one of the most dingbat ideas that I have heard of recently, and that is that we ought to legalize these drugs. It was amazing to me to hear a Federal judge say that we ought to legalize these drugs, it would help do away with the criminality of them. Do you have any thoughts on that?

Dr. HOLLOWAY. Well I was reading recently that Italy legalized the personal use of heroin a couple of years ago because of the tremendous problems they had with heroin and that they are estimating there are about 150,000 or 200,000 new heroin users since the legalization.



I think that crack is such an addictive substance that it is really a dangerous substance and it would be hard for me to see having it as a legal substance.

Mr. ROWLAND. Senator Kennedy mentioned methamphetamine, a new drug, ice. Are you seeing any of that coming into rural Georgia now?

Dr. HOLLOWAY. In one of our rural counties I was told last week that we had two children, both under the age of 15, who were admitted to a local hospital, one was placed in intensive care and was shipped to another hospital because of ice, and the other child was treated for a few days in that hospital and released. We are just beginning to see it and we are beginning to see heroin again because people use heroin with crack to kind of block the crash that crack gives, it kind of levels them out, so we are beginning to see more heroin again.

Mr. ROWLAND. Just one final question. How do you think that AIDS is going to impact our health care delivery system, do you think it is going to have a significant impact on it—what do you foresee there?

Dr. HOLLOWAY. I told my staff 3 or 4 years ago that within 10 years they would all know someone personally with AIDS and unfortunately it has almost come true just within 3 years. We only had 154,000 cases of polio, paralytic polio between 1950 and 1954 and virtually all of us older than 40 years old know people who had paralytic polio. We will have over a million new cases of AIDS during the 1990's, so it is without a doubt that we will all be touched by this disease. All of our local hospitals have already admitted several patients. They cannot get them transferred out because there are no centers that are set up in Georgia to really serve the State for AIDS care, so I think it is going to be the straw that really breaks the back of the kind of faltering health care system.

The CHAIRMAN. OK, thank you very much.

We are pleased to have the administrator of the Hancock Memorial Hospital, Gary Dollack, we appreciate very much your presence.

#### STATEMENT OF GARY DOLLACK, ADMINISTRATOR, HANCOCK MEMORIAL HOSPITAL, SPARTA, GA

Mr. DOLLACK. Thank you very much, Senator Kennedy and Congressman Rowland.

For the past 7 months I have been privileged to serve Hancock Memorial as its administrator. Prior to that I have had 25 years in service to rural hospitals in 6 different States. I appreciate the opportunity to come today and share a few of my thoughts with you.

Although this hearing is being conducted in Sparta, GA, which is without a doubt, a small, economically depressed rural community in the heart of the south, what you hear today can be readily applied to other areas as well. Rural hospitals throughout this Nation are in trouble. If our rural hospitals were the patient, the doctor would describe our condition as critical and the prospects of survival would be considered very grave.



During the past 2 years more than 160 rural hospitals have closed their doors, three of these were in Georgia. Residents of Fort Gaines, Heard and Turner Counties must now look elsewhere for hospital care. When a community hospital stops operating, child health care suffers, health care to the chronically ill deteriorates and access to health care is severely restricted. Sometimes the consequences are deadly.

Hancock County residents have first-hand knowledge of this. In the mid-1970's Hancock Memorial Hospital was forced to close. For 10 years the citizens were compelled to face life without ready access to hospital care. The people wanted their hospital back so badly that they pledged their property taxes to guarantee its operation. In 1985, Hancock Memorial reopened but at the cost of a heavy tax burden. Last year, as the Senator mentioned, one-third of the county's expenditures went to support the hospital. This year we are looking forward to cutting this burden in half. Still, the funds required will place a severe hardship on our taxpayers. One of the ways we hope to ease this strain is by working even closer with the community primary health center. Now that their new doctor is on board, I foresee working together for the benefit of both facilities. Through a sound cooperative effort, we can provide more ready access to our citizens.

Because of a lack of care, we in rural areas often see things that one would rarely find in urban locations. On three occasions at three different hospitals, I have seen diabetic patients come in for follow-up care after a lower-leg amputation and when the dressing was removed we found that their wounds were filled with maggots. With proper care, this just would not have happened.

Hancock Memorial Hospital provides care to many people who cannot afford to pay for that care. They have no coverage under Medicare, Medicaid, an employer-sponsored group health plan or private insurance policy. Last year we provided more than \$300,000 worth of care for which we were not paid. Fortunately Hancock County stepped in to assist with its subsidy. Most other hospitals do not have this kind of backing.

If Hancock Memorial Hospital were put on wheels and moved 50 miles in just about any direction, our rate of payment under the Medicare program would be increased markedly. After the Health Care Financing Administration applies all the factors to arrive at what hospitals are to be paid under Medicare, Atlanta area hospitals receive 43 percent more for the same care to the same patients. If Hancock Memorial were paid the Atlanta rates, our tax burden would be greatly reduced, if not eliminated.

Hancock Memorial is not alone. Rural hospitals in Georgia expect to receive \$26 million less than their costs for treating Medicare patients during 1989. Last year Congress acted to reduce this unjustified gap in payment and we are truly grateful. Hopefully Congress will continue to address this very vital issue. Rural hospitals throughout this Nation are striving valiantly to fulfill our mission of providing the highest possible quality care to our patients, but we need relief.

If we are to continue in operation, a number of actions could be suggested. First, we should find funding for care for those who are currently falling through the cracks, those who have no or little in-

surance and do not qualify for other coverage and who cannot afford for that very necessary care.

Another step would be to continue to reduce or hopefully eliminate the differences in Medicare payments between urban and rural providers. If health care is to be a right, readily accessible to all, as Senator Kennedy mentioned, and not just a privilege of a few, the means to adequately finance that health care, that right, must be found.

Thank you again. [Applause.]

The CHAIRMAN. Thank you very much. We appreciate very much your testimony and you obviously have a keen insight into the problem. It is very valuable for us to get that insight.

I suppose I would be interested in having you just think through what guidance and advice you give to those who are trying to deal with, trying to assure that you are going to have access to good quality care in rural America, recognizing that it is extremely important to have health care facilities. Without it, it takes a long time to get to other kinds of health care facilities, and endangers health. We know that these are areas where there are important health care needs and we are faced with different crises in the rural areas because of the more senior population with their particular needs, indigent population and their particular needs.

We know also that there are a number of rural hospitals that are not being utilized to the extent that they should be. We know that if you close some of the rural hospitals and have people go into places which are larger, that it is a greater threat to the health care of those individuals that have to go there and then it puts an additional burden on those individuals that live in those urban areas, which they may very well resent.

So how do you come to the balance in this, where you have facilities that may not be utilized and we cannot have the latest equipment, the highest technology in every kind of rural hospitals all over this country—how do you reach those balances? What guidance can you give us as to how to examine that in a way that is in the interest of the health of the people in rural America in enhancing that quite frankly, particularly given the new kinds of needs that we are going to face and also balance that against the kinds of resources that we have available?

Mr. DOLLACK. I think one of the things we have to look at is the various ways we discriminate against the health care providers in rural America. Not only do hospitals receive less, pharmacies receive less, physical therapists receive less, doctors receive, I believe in this State, 20 percent less because they practice in rural America, yet we are trying to come up with ways to entice physicians to move to rural areas where they are so badly needed. Atlanta has a glut of physicians, we need two full-time doctors here to adequately take care of our citizens.

Those of us that have facilities that are not totally utilized need to look at other ways to use those facilities in an economically viable way. Our hospital has 19 beds that are closed out of the 52 for which we are licensed. We are also approved to provide 10 swing bed facilities. We are not totally using that because it has not been economically feasible for us. We hope that will change the

first of the year when the State of Georgia covers swing beds under its Medicaid program.

The CHAIRMAN. Congressman Rowland.

Mr. ROWLAND. I really do appreciate, Gary, you focusing on this differential between the urban and rural areas. I have never really understood that.

Mr. DOLLACK. I did not understand it either.

Mr. ROWLAND. Well an x-ray machine costs just as much in a rural area as it does in an urban area, equipment of any kind, supplies all cost just as much. Maybe personnel might be a little less expensive at one time, but I am not sure that is true. Of course, Senator Kennedy knows we have been working very hard to remove that differential and the reconciliation this time did make a significant change because rural hospitals will be reimbursed 3 percent above the inflation rate, urban hospitals will be on the minus side to try to address some of that differential, so I am really pleased that you looked at that.

You mentioned the swing beds. You know, you cannot utilize your beds for nursing home care because of regulations that exist now, only a certain percentage of them.

Mr. DOLLACK. That is correct.

Mr. ROWLAND. So you know, if that was removed, those beds could be utilized a lot better because there is a significant need for those beds.

Let me just make one other comment, I almost get on my soapbox when we start talking about rural health care, but since 1983 with the advent of the DRG payment system, there have been more than 200 rural hospitals that have gone out of business because of that. They form the center of communities in many instances and add a lot to the quality of life, and I think it is so important that we do all that we can, just as you are doing here in Hancock County as individual citizens and as the local community to preserve those hospitals.

I really appreciate your testimony in that respect. Thank you very much.

Mr. DOLLACK. Thank you.

The CHAIRMAN. Thank you all very much, we appreciate your presence here.

We just have a few more moments for our hearing. We would like to perhaps invite, in the time that we have left, about 10 or 12 minutes, those that would like to make some kind of presentation, we will hear them. First, we have Dr. Green, who I see in the back of the room. Dr. Green has been in the front lines of the fight for rural health more than 45 years as a physician serving a rural area, a medical educator, and public official. When I first discussed with Congressman Rowland about the possibility of having a field hearing in Sparta, he told me that George Green was one of the people who could help us most and he was certainly correct. He has given us valuable assistance in preparing for the hearing, and I wonder if we could ask Dr. Green to make whatever comments he would like, and then if there are others who would like to line up behind him. At the end of Dr. Green's comments, we will take the time we have left and the number of people, and divide it up and go from there. For those that will not be able to get a chance to



speak, we will have a staff person that will remain here and take your names so that you can make whatever comments you would like, and we will make that part of our record.

Dr. Green, we are glad to have you.

#### STATEMENT OF DR. GEORGE GREEN, A PHYSICIAN, MEDICAL EDUCATOR AND PUBLIC OFFICIAL

Dr. GREEN. Thank you, Senator Kennedy, we are from an historic city and historic county and we are all proud of the events we have been able to overcome here and work together for the last few years, we have made considerable change, one is the library that we are in.

We would like to thank the State and Federal Government for all their cooperation in helping us with these facilities.

The big problem with us right now, we feel, is what Mr. Dollack reported to you—medical care in rural areas is being discriminated against. The first and biggest thing that would help us, if these were alleviated, and put us on a par with everybody else. There is nothing cheaper in the rural areas as far as medical care is concerned. All the equipment we buy comes from Atlanta with time and distance on a service call. Our relief help for the nurses and technicians, same thing, we have to pay a much higher rate and we have to pay mileage when they come.

We just want to be treated fairly and we feel that working together like we have been in recent months and recent years, that we can overcome anything and keep this hospital going and provide good medical care for this community.

The CHAIRMAN. Thank you very much, Dr. Green, we appreciate it very much. [Applause.]

Step right up to that mike there and I will ask if you would identify yourself for us, give us your name and where you live and if you can keep the remarks to maybe a minute, we would sure appreciate it, this will give a chance for others to make what comments they would like.

#### STATEMENT OF CHRISTIE WALKER, HANCOCK COUNTY, GA

Ms. WALKER. I am Christie Walker, I live in Hancock County and I have a lot of bills, I am a sick person, I have a cardiac condition which I had surgery for in March and I have glaucoma and a lot of other complaints, and I have a very, very low income. I would just like to say that if I do not have transportation back and forth to Augusta, that I have to postpone appointments.

I can see in the dark but not in the light. I am not total but my doctor says that I have high pressure in the 30's when he wants me to be in the teens and in that way, I am having it hard. I live off of Social Security.

The CHAIRMAN. Thank you very much. Next.

#### STATEMENT OF LILLIAN MACAFEE, WASHINGTON COUNTY, GA

Ms. McFEE. I am Lillian MacAfee from Washington County. I have a son who is now in Alabama, in a nursing home because the State of Georgia has no place to care for a vent-dependent quad. A ventilator is a machine that breathes for him, he is paralyzed from



ear level, jaw level down. He has been shipped—after his insurance, a million dollars that lasted for 2 years, one year in a hospital and one year in an apartment with continuous care, until that million dollars was used up. He was sent then to Ohio to a nursing home.

Larry is an engineer, perfectly good mind and nothing. He do not need to be in nursing homes, even if there was one in Georgia, but there is not unfortunately, so now he has been shipped to one in Alabama from Grady Hospital in Atlanta.

Most of the news media are aware that Larry won a court case back in the summer to turn his ventilator off. He will be shipped from Alabama the end of April, 1990 back to Grady Hospital and before he goes back there, he will say it is time.

Do we want to leave people like this? If he had some permanent home—Canada has group homes for vent-dependent quads, they operate much cheaper than a nursing home. The six men in the original one hire their own attendants, you can be trained—Larry's family has been trained and we certainly have no medical background except his oldest sister who is a nurse, but we have just many, many medical needs.

Larry is not sick, he is handicapped.

Thank you.

The CHAIRMAN. Thank you.

#### STATEMENT OF HOWARD MOORE, MACON, GA

Mr. MOORE. Senator Kennedy, it is very, very wonderful that you took the time, you and Congressman Rowland, to come here. I talked to your colleague before.

My name is Howard Moore. I talked to Sam Nunn and he gave me the right to give you a booklet about some things we have been doing.

Back in 1974 there was a law passed giving people the right to designate \$10, \$20, or \$30 dollars of their tax money to go so rich corporations could not buy the politicians. Under that program for citizens to designate some portion of their tax money for political campaigns, that made the system again more democratic. Under that program billions of dollars have been raised to help people elect their officials from your vote, not from a bought situation.

I wrote a program and took it to Washington, DC—

The CHAIRMAN. I will give you just a couple more—another 15 seconds because we have two or three people behind you.

Mr. MOORE. Thank you. Let me give you a program.

The CHAIRMAN. All right, thank you very much. We are going to take three more.

#### STATEMENT OF CYNTHIA SMITH

Ms. SMITH. My name is Cynthia Smith and the message that I would like for you to take back to the Congress is to build a stronger EPA, a Federal EPA, to protect the environment because without the environment we will all be sick and die.

If we let the polluters continue to try to assault black communities and other minority communities, the world cannot live without a safe, strong environment, so health care is secondary, mother

nature should be first. And everybody should really get back to nature—depending on hospitals and doctors and all that, if you remember your grandmother used to get herbs out of the woods and give you some tea and you would feel better, so I think we really need to be trying to get back to nature and we need a stronger environment.

We want this assault on the black communities to stop because we are under siege right now.

The CHAIRMAN. Thank you. Last two right now.

#### STATEMENT OF ALTON SPELL, JR., LOUISVILLE, GA

Mr. SPELL. Good morning, my name is Alton Spell, Jr., from Louisville, GA and I am with the Rural Health Outreach Program.

Senator Kennedy, first of all I would like to thank you for taking a look, you and Representative Rowland, for at least addressing the issues of rural health care. I would just like to say for your information that one of the problems that we have had in looking and observing maternal and infant care, for your record, one of the things that our mothers in our tracking program have found is a lack of transportation that is causing a problem with a lot of the infant mortality in the rural areas.

Also we would like to let you know that one of the things that is handicapping some rural health care in our area is the allowance of only 12 visits to the doctor per year under the Medicaid system within the State of Georgia. We would like to advocate that this should be increased because many times there are persons who need ongoing health care and they cannot get health care with that particular limit.

Clients must return for final application on assistance grants in our community and we feel that this should be limited within your program.

Also, speaking from a rural area, we would like for you to try to mandate equal funding in Medicaid levels to rural hospitals because we have a hospital in Jefferson County, the same as Mr. Dolack's, who is having a \$300,000 deficit in a county that has only got taxpayers of about 35 percent, who are funding most of the county, the rest of them are not able to provide taxes in that area.

Also, we would like to thank you, Senator Kennedy, for accepting Shawanda Kelly's input into this hearing this morning. Thank you very much.

The CHAIRMAN. Thank you. Our final spokesperson here.

#### STATEMENT OF LILY WARREN, SPARTA, GA

Ms. WARREN. Thank you.

I would like to thank you, Senator Kennedy. My name is Lily Warren, I am a nurse in a program called Community Care Services.

Right now we are a Medicaid waived service so that means every 3 to 5 years we have to go back and appeal to HCFA for money. What we are asking is that Community Care Services programs be included in the Medicaid options programs just like dental services, just like nursing home services, because right now we have a waiting list. Our fiscal year starts in July, it is Decem-

ber, we are out of money so we cannot serve people like Ms. Baity's mother. The aim of our program is to assist older Georgians to stay in their homes and not have to go to institutions.

So we ask that you would also consider bringing in to MAO those who make more than the SSI limit plus make their income be able to be diverted to their caregiver, not just to their spouses, but to their daughters or siblings who take care of them.

Please admit Community Care as a Medicaid option program so that our money comes directly down and we do not depend on State funds or anything, to serve these people who want to stay in their homes.

Thank you. [Applause.]

The CHAIRMAN. Thank you.

How is anybody to say no to that presentation.

[Additional statement and materials submitted for the record follow:]

**AMERICAN ACADEMY OF FAMILY PHYSICIANS  
POSITION PAPER****ACCESS TO HEALTH CARE**

One of the greatest challenges facing the health care delivery system is ensuring access to health care services for the uninsured. The number of Americans without insurance of any kind presently is estimated at 37 million and that number is growing. Unless steps are taken to address this problem immediately, it can only become more acute in the years ahead and more difficult to resolve.

The American Academy of Family Physicians long has espoused the view that the family physician functions as his or her patients' advocate in all health related matters. The Academy's Board of Directors believes that this organization and the family physicians it represents also must serve as advocates for those 37 million Americans who do not have access to health care through insurance coverage.

For the past several months, the Academy's Board of Directors and Commissions on Health Care Services and Legislation and Governmental Affairs have reviewed various proposals for improving access to care. At the June meeting of the Board of Directors, both the Commission on Legislation and Governmental Affairs and the Commission on Health Care Services presented recommendations on a draft position statement on access to care, which they had been asked to review. Many of these recommendations were incorporated in a revised "AAFP Position Statement on Access to Health Care for the Uninsured" which was reviewed and approved by the Board of Directors at its August meeting. A copy of this statement is attached as Appendix A.

**RECOMMENDATION**

The Board of Directors recommends that the Congress of Delegates approve the attached statement entitled "AAFP Position Statement on Access to Health Care for the Uninsured" and adopt



the position that improving access for the uninsured should be pursued vigorously by the American Academy of Family Physicians as a high priority.

AAFP Position Statement  
on  
Access to Health Care for the Uninsured

During the decade of the '80s, there has been a dramatic increase in the number of Americans who are without health insurance of any kind. Estimates place the number of uninsured Americans at 37 million. While the public opinion polls repeatedly have indicated widespread agreement that everyone has a right to adequate health care, those same polls evidence little enthusiasm for improving access through increased taxes. The dilemma, then, is how to address a societal problem of significant proportions -- the lack of access to health care for millions of Americans -- given our finite financial resources and a reluctance among both policy makers and the public to significantly increase taxes to provide insurance coverage. Despite this dilemma, however, the AAFP believes the issue of access to health care for the uninsured must be addressed as one of this Nation's highest priorities.

One approach which has received such attention in recent months is that of requiring employers to provide health insurance coverage for their full-time employees. While this approach would not result in major tax increases and is attractive insofar as approximately 2/3 of the uninsured are employees or dependents of those employed, it could pose substantial hardships for small businesses. Additionally, a significant segment of the uninsured population, who generally are poor or near poor, would remain uninsured under a program which covers only employees and their dependents.

The Medicaid program, as it currently is structured, conditions eligibility on requirements which vary significantly from state to state and which are based on each state's definition of eligibility for cash assistance. Less than half of those below the federal poverty level qualify for Medicaid benefits and the scope of benefits also varies from state to state. Because Medicaid payments for services are substantially discounted, a two-tiered system has developed under which Medicaid patients' choices of providers are limited and they do

not have access to "mainstream" medical care. For these reasons the Medicaid program as presently constituted does not present a viable mechanism for addressing the problem of access for the uninsured.

It is the position of the Academy that the issue of health care for the uninsured can best be addressed through a system which primarily is based in the private sector but which also includes a substantially revised and expanded Medicaid program. Such a system should be phased-in over a period of time, should promote the concept that the uninsured must have access to primary care services as well as more elaborate medical technologies and should emphasize appropriate quality care, utilization and health outcomes. Under this approach, employers who employ more than a specified number of employees would be required to provide health insurance coverage for their full-time employees and the dependents of those employees. Other individuals who are not covered under employer-provided insurance would be entitled to participate in the restructured Medicaid program.

Consistent with the overall objective of providing access to the Nation's uninsured through a combination private sector/publicly funded program, the Academy supports the following principles:

- (a) Except in the case of small employers who employ less than a statutorily defined minimum number of employees, all employers should be required to provide health insurance coverage for their full-time employees and the dependents of those employees.
- (b) Mechanisms such as regional insurance pools should be instituted to minimize the impact on those smaller businesses which are not exempt from the requirement to provide insurance but for which the requirement may cause significant hardships.
- (c) Under the employer-mandated coverage, the employers should be required to pay a minimum percentage of the employees' insurance premiums and the employees should be responsible for cost sharing through payment of deductibles and co-insurance, with a maximum annual ~~cap~~ out-of-pocket expenditures.

- (d) A basic range of services as defined by AAFP policy on "Basic Health Care" should be included in the employer-purchased coverage. Current AAFP policy on "Basic Health Care" reads as follows:

Basic health care consists of only those medical services which are necessary to prevent, diagnose or treat disease and injury and which are provided in a cost-effective, efficient manner and in an appropriate setting consistent with patient needs and quality of care considerations. Unproven, experimental and purely cosmetic services are excluded from basic health care. The elements of basic health care are as follows:

- o Prenatal and maternity care
  - o Infant care
  - o Periodic evaluation and screening
  - o Preventive medicine, patient education and immunizations
  - o Dental care
  - o Treatment and rehabilitation of injury
  - o Diagnosis and treatment of illness and dysfunction
  - o Care of elderly persons
  - o Terminal care
- (e) The Medicaid program should be revised to provide uniform, national eligibility criteria based on income rather than eligibility for public assistance and should include provisions whereby the homeless and the medically uninsurable are covered.
- (f) Medicaid coverage should include a uniform, basic range of services consistent with those required of employer-sponsored insurance plans and Medicaid payment for services should be on a par with Medicare payment and should be established through a resource-based relative value scale.
- (g) Individuals and their dependents who are not otherwise covered under an employer-sponsored insurance program and whose income is at or below the federal poverty level should be fully covered by the Medicaid program.

- (h) Individuals and their dependents who are not otherwise covered under an employer-sponsored insurance program and whose income exceeds the federal poverty level should be given the option to purchase Medicaid coverage with the premium determined on a sliding scale basis relative to income. Deductibles and coinsurance should be paid by those purchasing Medicaid coverage and also should be determined on a sliding scale basis, with a maximum annual cap on out-of-pocket expenditures.

Implementation of the foregoing principles will result in a clearly-articulated national health policy which has as its three major components Medicare, employer-provided coverage and a restructured Medicaid program, through which all of those not otherwise covered can be insured. The American Academy of Family Physicians believes that with these three programs in place, every American citizen will be assured of having access to a broad range of essential health care services.





## EMERGENCY FUND FOR THE MEDICALLY INDIGENT, INC.

141 Lakeshore Circle, N.E.  
Milledgeville, Georgia 31061

A United Way Agency

December 14, 1989

Senator Edward Kennedy  
Senate Office Building  
Washington, D. C.

Dear Senator Kennedy:

Thank you for coming to middle Georgia. Attached is information on a volunteer program operating through the Baldwin County Health Department. It is a beautifully simple program, but funding care for sick people should not be left to tiny points of light. I fear we may be in danger of using sickness of the poor as a means of population control.

To address the problem of "shortage" of medical care for the poor, which is in fact the need to provide universal access to health care, we might establish primary care (medical treatment) facilities in every county in the nation where it does not now exist.

Located, preferably, in county health departments, such treatment services would complement the preventive nature of public health care. Also, the idea tends to emphasize economic support of wellness rather than illness; and, I do not believe it would be more expensive than lengthy hospital or nursing home care, especially if run on a sliding fee scale. [The American Public Health Association suggests that it may provide a measure of competition to the private medical area that would help reduce health costs generally. (C.A. Miller & Merry-K. Moos, Local Health Departments, Fifteen Case Studies, Chapel Hill, APHA, c 1981, p.6)]

If it would only make matters worse to tax the drug companies to support whatever measures we take, then surely the exorbitant cost of prescription medicine merits an investigation.

Again, thank you.

Sincerely yours,

A handwritten signature in cursive script, appearing to read "Earline Ham", is written over the typed name.

Earline Ham



# EMERGENCY FUND FOR THE MEDICALLY INDIGENT, INC.

141 Lakeshore Circle, N.E.  
Milledgeville, Georgia 31061  
A United Way Agency

Questions and answers about a local health service ...

Q What does EFMI do?

A EFMI receives and spends donated money in a program to pay doctors, dentists, pharmacies and sometimes local transportation for Baldwin County citizens who need medical attention and cannot afford to pay for it.

Q How does a person needing such a service go about getting it?

A Persons who are ill and without money or insurance to pay for their medical care go to the Baldwin County Health Center on Barrows Ferry Road (in the former Bone Brickyard/Griffin Pipe office building). There, he or she talks with a nurse. In considering the person's condition and other circumstances, the nurse may decide to draw on funds available through EFMI. If so, she contacts someone in the medical community (doctor, dentist, pharmacy) and arranges for the needed service; and the fee to be paid by EFMI is set. The nurse completes a brief form with the patient. That form authorizes EFMI to pay the bill.

Q Then a person needing help from EFMI does not have to contact the organization directly.

A No. No member of EFMI comes between the nurse and patient or between the nurse and medical practitioner. This procedure assures patient privacy and professional confidence, and it avoids unnecessary delay. In the EFMI program, with their extensive knowledge of options available in medical services, nurses have full discretion.

Q If someone gets sick at night or on a weekend and has to go to the county hospital emergency room, will EFMI pay the bill?

A No. EFMI services are available only through the Health Center and between the hours of 8:30 and 4:30, Monday through Friday. Only public health nurses may authorize services to be paid from the fund.

The county government contributes to the hospital to assist with care for the poor in the emergency room. We believe that EFMI cuts down on emergency room demand and lessens the need for hospitalization.

Q Is there a limit on what EFMI will pay on a medical bill?

A EFMI will not pay past-due bills. The program will pay the amount written by the nurse on the "authorization" form. Most of the time this is the entire charge for the specific service rendered. Sometimes, however, the medical provider will accept the payment from EFMI and then bill the patient for an additional amount. This is beyond the control of EFMI, and the patient is told by the nurse when this will be the case.

Prescription medicine cost can run into the hundreds of dollars. Nurses are kept informed of the balance on hand in the EFMI account and must make judgments about how much of a cost we can pay based on how much money is available.

Q Does EFMI pay hospital bills?

A No. If a physician (to be paid by EFMI) recommends hospitalization or extended treatment for a patient, then public health nurses may assist in making arrangements for follow-up care, which might be provided through a state-supported hospital. EFMI could not afford to pay for such care.

Q Where does EFMI get its money? What does it cost to administer the program?

A The major source of funding is United Way. Additional fund-raising is necessary to support the program. There are no salaried officers or employees and Board members pay the cost of administering the program. That amount in 1988 was \$209. (That does not include value of donated time.)

Q How long has EFMI been in operation? What has it achieved?

A EFMI began operation in January of 1985. In 1988 with \$5500, EFMI purchased for 253 persons of all ages:

- 151 pharmacy visits
- 121 physician visits
- 9 dentist visits
- 7 instances of transportation
- 2 instances of medical supplies
- 1 X-ray
- 1 laboratory test

Q If I wanted to make a donation to EFMI, where would I send a check?

A Send donations to EFMI, 141 Lakeshore Circle, NE, Milledgeville, Georgia 31061. A special card is mailed to the family of persons in honor of whom memorial gifts are given.

REMEMBER--EVERY PENNY DONATED GOES TO PATIENT SERVICES!

# The Union-Recorder

Georgia's 'Old Reliable' Newspaper

Vol. 171 No. 6 14 Pages

Milledgeville, Georgia Tuesday, January 10, 1989

© 1989 The Union-Recorder

## Fund finding it harder to aid medically needy

By Binky Strickland  
Lifestyles editor

He is 63 with a cardiac condition. He has no money to refill medication vital to his survival.

Emergency Fund for the Medically Indigent pays the pharmacy cost, preventing the interruption in the regular medication.

She is a 50-year-old diabetic. Due to a family crisis she is unable to buy insulin. Emergency Fund for the Medically Indigent covers the cost.

The list of Baldwin County residents helped each year by the local fund is a long one. They are people who "fall through the cracks" — people who do not qualify for other types of assistance for a variety of reasons.

Some of the people who have received aid from EFMI are employed but have no health benefits. Some have lost their jobs and have families to support. Some are on a fixed income. Others are too young for Social Security help. All of them have immediate needs for life-saving prescription medicine or medical attention.

Earline Ham, president of the board of directors of the fund, gave an example of one type of person the fund helps.

"We've had people who have cancer," she said. "They were working but had to leave their jobs. The bills piled up, and even if they had insurance they can't wait for payment to come in. They need immediate help."

For years, EFMI has managed to provide that help. But Ham said rising medical costs and lack of donations may take its toll on the program.

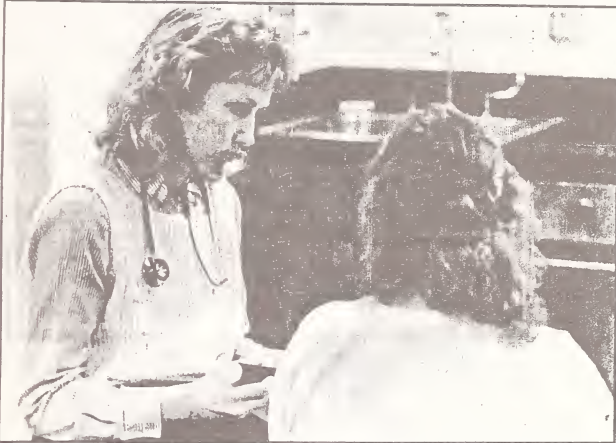
"We need some support now," Ham said.

EFMI IS A PROGRAM administered through the Baldwin County Health Department, which receives and spends donated money to pay doctors, dentists, pharmacies and sometimes local transportation for citizens who need medical attention and cannot afford to pay for it. It has been in existence as an incorporated non-profit organization since 1965. Yet its roots reach back much further.

Before EFMI was formed, nurses at the Health Department took it upon themselves to get medical attention and prescription drugs for indigent patients who didn't qualify for any other kinds of assistance. To raise money they solicited various organizations in Baldwin County.

"EFMI actually started some time back when Health Department nurses felt people needed help and went beyond the call of duty to provide it for them," said Ham.

Ham said funds from local clubs and organizations became scarce during the recession of the early 1960s. In 1964, in order to qualify to receive funds from United Way, EFMI was formed. Provisional tax-exempt status was obtained in early 1965 and permanent status in 1967. EFMI has a 10-member board of directors who are community volunteers. There also is a community advisory committee.



SAM WALTON/Staff Photographer

Nurses at Baldwin County Health Department consider each case, then determine who will receive help. Registered nurse Patsy Pollett, who deals with many EFMI recipients, counsels a patient.

RECIPIENTS FIND their way to EFMI through the nurses at the health center. The nurse considers the person's circumstances and makes a decision whether to draw on EFMI funds. If so, she contacts someone in the medical community and arranges for the service. The fee to be paid by EFMI is set.

Ham said the nurses have full discretion, and no member of EFMI comes between the nurse and patient, ensuring privacy, confidentiality and preventing delay.

EFMI does not pay for emergency-room visits or hospital care, Ham said.

"We cannot afford that," she said. "We feel like through our program hospital stays and emergency-room visits are avoided because we provide preventative care."

United Way has supported the program for the past three years. However, the money EFMI receives from the agency is only about

half the amount needed to provide its service. For example, EFMI receives \$2,800 for 1989. Last year EFMI provided care for more than 280 indigent people at a cost of \$4,770, and costs are going up.

EFMI depends heavily on direct contributions by individuals and organizations to make up the deficit, Ham said. But many efforts to solicit donations through letter-writing campaigns have literally failed, she said. Consequently, much time and effort was spent last year on fund raisers such as raffles and yard sales.

"The fund-raising is becoming more and more time consuming," said Ham. "What we need is for people to respond with some support. We welcome outright gifts and memorial gifts. It's a tax-exempt agency."

Ham said that in 1988 the program provided 121 visits to physicians, 151 pharmacy visits

and nine visits to dentists. It also provided transportation, medical supplies and lab tests.

She said she felt the program was exceptional because it is streamlined with no red tape involved, which prevents taking up nurses' valuable time; there is no waiting period for the recipients; and it serves as a preventative measure against more serious and costly illness.

"Also, we feel that when people are ill and have sick family members, you have stress, depression, anger and frustration," Ham said. "It feels this program cuts down on that. It supports family cohesiveness."

Ham said very few of the recipients return for more aid.

"Last quarter, out of 69 people who came through the program, five came back twice and one came back three times," Ham said. "As soon as they are able to help themselves, that is what they do."





# POLICY STATEMENTS

*Adopted October 13, 1989  
Atlanta, Georgia*

## The ACCG Policy Development Process

The Association County Commissioners of Georgia's policy committee structure facilitates a coordinated policy development process. Through an open exchange of ideas concerning topics of mutual interest to county governing authorities in Georgia, the Association can strengthen its voice in the federal and state legislative process.

The committee structure provides a forum for members who want to participate in decision-making on legislative positions which the Association establishes. Also, the committee format allows ACCG to solicit the expertise of county officials from throughout Georgia.

ACCG has established six standing policy committees to work on the issues which confront county commissioners: General County Government, Taxation and Finance, Public Safety, Health and Human Services, Natural Resources and Environment, and Transportation. Policy committee membership is comprised of commissioners as well as other elected and appointed county officials. All member counties may be represented by one or more local officials.

Committee appointments are made by the president of the Association shortly after the ACCG annual meeting each spring. Policy committees set their federal and state issue agendas on an annual basis, and determine the frequency of committee meetings after the annual agenda has been prepared.

Policy committees of the Association have two primary tasks: First, they are called upon to develop recommendations and resolutions which will be forwarded to the entire ACCG membership as proposed Association policy. Their second task is to provide an educational forum for ACCG members. In this regard, policy committee members have an opportunity to participate in comprehensive programs, training sessions and fact-finding tours. These efforts are undertaken to help members understand better the complexity of issues which confront them in their respective roles as county officials.

The policy statements that follow represent the work of each of the six policy committees from July 30, 1987 to the present. Approximately 320 county officials took part in committee deliberations this year. Their recommendations were adopted by the ACCG membership at the Legislative Conference in Atlanta October 12 and 13. □

## 1989 RESOLUTIONS COMMITTEE

John Jeffreys, Clarke County  
*Committee Chairman*

Robert W. Wommack Jr., Washington County  
*Conference/Committee Parliamentarian*

Curtis Brantley, Ware County

Jesse Brown, Taliaferro County

Same Brownlee, Fulton County  
Fred DeLoach Jr., Lowndes County

Bette Grier, Early County

Gene Hobgood, Cherokee County

Curtis Jenkins, Monroe County

Leroy Johnson, Coweta County

Manuel Maloof, DeKalb County

Shaw McVeigh, Glynn County

Connie Meier, Dougherty County

Frank Moore, Bartow County

G.B. Moore III, Jones County

Walker T. Norman, Lincoln County

Philip L. Secrist, Cobb County

David Perry, Carroll County

Houston Porter, Houston County

Jack Rowan, Catoosa County

Curtis Segars, Hall County

Bud Sosebee, Rockdale County

Mike Stewart, Liberty County

Mac Thornton Jr., Elbert County

Kimball A. Warnock Sr., Effingham County

Chester Wilkerson, Peach County

## ACCG Policy Committee Staff

Telephone  
404-522-5022



Jerry R. Griffin  
*Executive Director*

## HEALTH AND HUMAN SERVICES

Mounting costs for health programs compounded by the drug epidemic and the related problems of broken families, high-risk infants and AIDS, are exerting continued pressures for additional county funding at a time of scarce local resources.

Health and human service programs are critical to our communities' stability and economic vitality, and Georgians who have "fallen through the cracks" of existing state and federal programs are looking to county governments for help. ACCG believes that the partnership between the federal, state and local governments for these functions must be renewed and that counties should be directly included in decision-making for health and human services at the local level. Against this backdrop, ACCG offers the following policy positions:

### Indigent Health Care

ACCG commends Governor Harris and the members of the General Assembly in establishing the Access to Health Care Commission to make recommendations for comprehensive statewide solutions for providing health care to medically indigent Georgians. The cost of indigent health care is significant in many counties since county and other locally assisted hospitals serve as providers of last resort for those with no other medical coverage. The Association, as well as the State Health Policy Council and other groups, has called for such a body for several years; ACCG pledges full cooperation with the commission.

ACCG recommends that a valid formula be used to establish a uniform statewide standard for indigent health care. It is suggested that the standard be determined by comparing Georgia's per capita income to the national per capita income and then determining a percentage to be used to apply to the federal poverty level. It is further recommended that the Division of Family and Children Services be designated as the agency in each county to determine indigent eligibility.

### Medicaid Eligibility

The Association believes that the Medicaid program, the federal-state partnership providing health care for the disabled, poor and low-income pregnant women and children, should be Georgia's first line of response to the indigent health care crisis since federal dollars match state contributions on an almost two for one basis. Therefore, ACCG endorses the expansion of our Medicaid program to the extent allowable under federal guidelines in order to provide coverage for all potentially eligible Georgians who would otherwise be medically indigent.

### County Boards of Health and Local Health Care Planning

ACCG commends the Georgia Department of Human Resources (DHR) in establishing education programs for county commissioners on the role of county health departments. The Association believes that county governing authorities and local boards of health have vital roles to play in planning for the needs of their communities and should have essential information about their health department's services, along with others in their health district, to do this.

ACCG therefore reaffirms its commitment to working with the DHR and calls for the development of regular written reports from health district directors to local boards of health and county governing authorities describing local public health and mental health/mental retardation/substance abuse (MH/MR/SA) programs, funding matters, client fees and related detail, along with contrasting information about health departments in other counties within the health district and information on sources of grants or other funding available for application. The Association further suggests that consideration be given to establishing district-wide boards of health composed of the chairmen of each local board of health within a health district. These district-wide boards could examine the needs of their region for public health and MH/MR/SA services and provide advisory information to individual local boards of health.

### Support for County Health Department Programs

The state-county partnership providing public health and mental health, mental retardation and substance abuse (MH/MR/SA) programs through county health departments has served many Georgians, but attention must be given to the strength of this partnership if these essential services are to continue to serve all those in need.

Grants-in-aid to counties based on matching formulas are the basic building blocks of the state-local partnership, but state support of these has not increased since the 1970s except for salary raises for health department staff. As a result, county support of health department programs has been rapidly increasing and constitutes a significant portion of county expenditures. Therefore, ACCG supports the equitable distribution of grant-in-aid funding and the Department of Human Resources' (DHR) FY 91 budget request reflecting a 4 percent increase in grant-in-aid for both public health and MH/MR/SA and further suggests that additional funding be appropriated.

ACCG also supports related state budget requests assisting county health department services. These include, but are not limited to, the DHR's request for 247 Medicaid Eligibility Workers to screen clients on-site; \$14.9-million for Community Services for the Mentally Retarded; \$1.9-million for Adult Health Promotion programs; \$319,000 for migrant health programs; \$299,000 for TB programs; \$327,000 for sexually transmitted disease programs; \$1.8-million for better regulation of personal care homes and \$345,000 for other local projects. Similarly, ACCG supports the Department of Medical Assistance's FY 91 improvement request for \$1.04-million in state funds to increase the reimbursement rate to community mental health centers.

### Local Family and Childrens' Services (DFACS) Boards

Welfare and social service programs administered through local DFACS Boards provide critical assistance for many Georgians, and individual county contributions augment these services. Therefore, ACCG supports the Department of Human Resources' FY 91 budget request reflecting a 4 percent increase in state grant-in-aid to these agencies.

### Rural Health Care

ACCG believes that the availability of health care resources in rural areas is as important to economic development as other infrastructure and commends Governor Harris and the General Assembly for legislation and appropriations to recruit doctors into underserved areas and to assist rural hospitals. More work remains to be done, however. Therefore, the Association supports full implementation of the 1988 recommendations of Governor Harris's Rural Hospital Task Force and further suggests legislation be enacted whereby the state would protect health care providers in underserved areas from liability claims arising in the normal course of their practice in order to attract and retain their services.

ACCG also recommends full funding of the Department of Medical Assistance's FY 91 budget improvement requests increasing reimbursement rates for hospital services and to disproportionate share hospitals; the Department of Human Resources' FY 91 budget improvement request of \$478,000 to attract individuals into the public health profession, as well as the State Medical Education Board's request of \$75,000 for loans under the Physicians for Rural Assistance Act.

### Support for County Emergency Medical Service Programs

ACCG commends the House Motor Vehicles Committee for

responding to the call of the Association for a study of sources of assistance to counties in financing local emergency medical services (EMS). The cost of EMS is typically not recaptured by fees and third party reimbursements in areas with a low service volume. As a result, counties finance over 60 percent of these critical services. Therefore, ACCG supports legislative proposals and appropriations for EMS subsidies, grants, loan programs or other types of state assistance.

The Association also recommends funding of the Department of Medical Assistance's FY 91 budget request of \$314,000 in state funds to increase the Medicaid reimbursement rate for emergency ambulance transportation.

### **Emergency Medical Technician Ambulance Staffing**

ACCG reaffirms its opposition to reducing, either by rule or legislation, the number of certified emergency medical technicians (EMTs) currently required on county ambulances, both to ensure proper care to citizens and to contain county liability for the quality of care provided.

The Association supports increased training resources for EMTs and commends the General Assembly in passing legislation along with the efforts of the Georgia Department of Human Resources to help county governments establish appropriate procedures to enhance the quality of care provided by EMTs throughout the state.

### **Hospital Authority Appointments**

The Association believes it to be highly desirable that hospital authority members have an understanding of county revenue resources and constraints and therefore supports revisions to existing state law designating the commission chairman or sole commissioner of each county, or his/her representative, as a member of the county hospital authority on single county authorities.

### **Certificate of Need Program**

ACCG recognizes that the health care industry is subject to complex interrelationships affecting the supply, cost, quality, availability and accessibility of health care services. The Association believes that these interrelationships must be managed to ensure that viable health care facilities are available where they are needed throughout the state at a reasonable cost to health care consumers, employers, insurers and taxpayers. Therefore, ACCG supports a strong Certificate of Need (CON) program in keeping with these objectives.

### **Maternal and Infant Health**

Recognizing that prenatal care is our only weapon against the tragic and costly problem of infant mortality, ACCG believes that adequate resources for pregnant women and children should receive high priority. Therefore, the Association recommends full funding for the Department of Medical Assistance (DMA) and the Department of Human Resources (DHR) FY 91 budget improvement requests in support of programs for pregnant women, infants and young children.

These include DMA's proposal to expand eligibility under Medicaid for pregnant women and infants in families with income to 150 percent of poverty and children up to age eight in families with income up to 100 percent of poverty, as well as \$1.445-million in state funds for Maternal Support Services and \$1.5-million to increase reimbursements for children's diagnostic services at health departments. Full support for related DHR budget requests for \$6-million will expand existing services and place perinatal care systems in an additional ten health districts, low birth weight prevention programs in another six health districts, obstetrical low-cost prenatal and delivery programs in another three health districts, as well as provide "Right From the Start" services for another 8,500 children.

### **Programs for Youth at Risk**

The Association is concerned about the problems of child abuse, children caught in a cycle of family poverty, alcohol and drug abuse,

teen pregnancy and juvenile delinquency. We commend Governor Harris and the General Assembly for establishing the Commission on Children and Youth and related bodies to address these critical issues. ACCG is committed to working with the commission on appropriate roles for county governments in efforts targeted at youth at risk and supports funding of grants to communities planning local programs and subsidies or other forms of assistance to counties implementing these.

The Association believes that the state should continue its strong role in protecting our youth, and supports full funding for the Department of Human Resources' (DHR) FY 91 budget improvement requests aimed at responding to this challenge. These include \$22-million in state funds for Services to Severely Emotionally Disturbed Children and Adolescents; \$8.5-million for Comprehensive Adolescent Health and Substance Abuse Services that will include linkages between health departments and schools targeting youthful drug involvement as well as specialized residential treatment programs at five sites; \$9.4-million to expand Protection and Placement Services for abused and neglected children statewide including the CASA program, and \$13.4-million to expand programs within the Division of Family and Children's Services to break the cycle of poverty in families. ACCG also supports the Council of Juvenile Court Judges' FY 91 request for \$1-million to expand the Permanent Homes for Children program.

### **Alcohol and Drug Abuse Prevention and Treatment**

The drug epidemic is both a human tragedy and a major factor in mounting county costs and property tax bills for virtually every program including law enforcement, the jails, health care and mental health and social services. ACCG commends Governor Harris in establishing the Commission on Drug Awareness and Prevention and pledges its full cooperation with the work of this body. The Association further supports legislative proposals for grants, subsidies and other forms of assistance to counties voluntarily implementing local programs to combat drugs.

ACCG believes that the state should take a strong role in preventing and treating substance abuse and supports the Department of Human Resources' (DHR) FY 91 budget request for \$3.1 million for Community Alcohol and Drug Abuse Services to include special programs aimed at rehabilitating drug-using women who are pregnant and/or have young children.

### **Acquired Immune Deficiency Syndrome (AIDS)**

ACCG reaffirms its position that AIDS is a human tragedy and calls for proper health policies at all levels, sound education for all Americans, and appropriate individual behavior to prevent transmission of this disease. The Association endorses the AIDS Five-Year Plan adopted by the Department of Human Resources (DHR) and recommends funding for the DHR's FY 91 budget improvement request of \$3.5-million for statewide AIDS Prevention and Management Programs which includes increased funding for Grady's Pediatric AIDS Clinic, as well as those requests for other programs aimed at preventing the linked problem of drug abuse. ACCG also supports the Department of Medical Assistance's FY 91 budget request for an AIDS waiver for Medicaid coverage for children with AIDS who might otherwise be indigent.

ACCG does not support mandatory AIDS testing programs for the general public since the cost of this effort would far outweigh any benefit that could result.

### **Aging Georgians**

The Association is concerned for many of our senior citizens, who under federal OBRA requirements may no longer qualify for care in most nursing homes, and supports full funding through the Department of Medical Assistance (DMA) for compliance with the OBRA law. ACCG also commends the work of the Senate Community Care Committee and supports the Department of Human Resources' FY 91 improvement request of \$11.6 million in state funds for Community Care Services through local DFACs boards



and Area Agencies on Aging, as well those for other programs for older Georgians. Similarly, ACCG supports DMA's request to increase Medicaid reimbursements to community care providers and revisions in physician Medicare reimbursement procedures to ensure timely and appropriate payment.

#### **Housing Trust Fund**

The Association supports the concept of a Housing Trust Fund available to counties seeking to remedy local housing problems, but is opposed to dedicating locally raised revenues on a mandatory basis, including the real estate transfer tax, to support it. Therefore, the Association supports GRFA's FY 90 supplemental budget request of \$3-million and FY 91 request of \$7-million both to implement the trust fund and to provide state matching dollars for McKinney Act grants for homeless assistance using General Treasury dollars.

#### **Homeless Support and Intervention**

ACCG acknowledges that homelessness constitutes a human crisis and commends Governor Harris and the Georgia Residential Finance Authority (GRFA) for establishing the Interagency Council on the Homeless as well as undertaking related efforts to respond to this challenge.

Recognizing that mental illness is associated with homelessness, ACCG also supports the Department of Human Resources' (DHR) FY 91 budget improvement request of \$29.4 million and the Department of Medical Assistance's related request for Comprehensive Services for the Chronically Mentally Ill to expand existing programs and implement services in another 15 counties. Similarly, the Association supports the DHR's FY 91 improvement request of \$1.9-million to support a range of other programs for the homeless.

*from the office of*  
**Senator Edward M. Kennedy**  
*of Massachusetts*

STATEMENT OF SENATOR EDWARD M. KENNEDY  
 ON THE HEALTH CARE CRISIS IN AMERICA

December 6, 1989

Health care should be a basic right for all, not just an expensive privilege for the few. My family has been fortunate in being able to obtain the best in health care, and it ought to be available to every family.

But today we face a crisis in the health care system that threatens the well-being of every American family in communities around the nation. Health care is the fastest growing failing business in America. The challenge is more serious than at any time since the enactment of Medicare in 1965, and no one is immune--young or old, rich or poor, city or farm, insured or uninsured.

The challenge we face involves four central problems. Each one of them is serious, and together they constitute a health care crisis of unprecedented dimensions. There are too many uninsured and underinsured Americans; there is not enough long term care for senior citizens and the disabled; health care costs are escalating out of control; and essential health care facilities in every part of the country are overburdened to the point of collapse.

The growing number of the uninsured is unacceptable. In 1979, twenty-nine million Americans were uninsured. Today, the number is 37 million, and it is increasing every year. Sixty million Americans have health insurance that even the Reagan Administration said was inadequate. Altogether, there are almost one hundred million Americans who do not have the protection they need and deserve--more than one-third of the nation. The sad fact is that half of all Americans hounded by collection agencies every year are in debt because they have medical bills they can not pay. Even those who are adequately insured today may be at risk tomorrow--if their employer drops coverage, or if the family breadwinner changes jobs or loses a job.

Two-thirds of the uninsured are workers or dependents of workers. They deserve health insurance on the job but they can't get it at an affordable price, because their employers don't offer it. One-third of the uninsured are unemployed. They

deserve a helping hand from government, so that no American is denied the fundamental right to health care.

One of the most troubling aspects of the current crisis is the devastating impact on children. In my view, every child in America deserves a healthy start in life. But too many fail to get it because their parents can't afford it and society won't provide it.

--One in every five children in America today--12 million children in all--have no health insurance coverage.

--Forty percent of poor children--more than five million children below the poverty line--have no coverage.

--Two out of three pregnant women who are uninsured do not get the low cost, effective prenatal care their babies need. Because of this neglect too many infants do not even survive the first year of life. America ranks a shameful 19th, behind eighteen other nations in infant mortality--behind Japan, Sweden, Finland, Switzerland, Canada, the Netherlands, France, Denmark, West Germany, Norway, East Germany, Spain, Australia, the United Kingdom, Belgium, Italy, Austria and New Zealand.

--Forty percent of children do not receive the basic childhood vaccinations that are the first line of defense against serious diseases.

--A quarter of all children have no physician. The only family doctor they know is the hospital emergency room.

America's children are the innocent victims of health care crisis and that means America is the victim too--because our children are our future.

Senior citizens face a crisis too. They have worked hard all their lives to earn a secure retirement, but their golden years are threatened by the high cost of long term care. A main reason why the catastrophic insurance program turned into a public policy catastrophe is that it failed to provide the protection senior citizens need most--affordable long term care.

Three million severely disabled elderly Americans need home care or nursing home care today. Forty to fifty percent of all

senior citizens alive today will need nursing home care at some point in the future.

Long term care is not just a problem for the elderly--it is a major burden for their sons and daughters as well. Few families are prepared--either financially or emotionally--to take full responsibility for meeting the challenges of providing long term care for parents who need it. These families deserve our help.

The soaring cost of health care and the unfair way we finance it are placing a heavy additional burden on the system. The national bill for health care today is \$500 billion--double what it was in 1980. Health costs are rising twice as fast as wages, and the costs for business have become a flash point for both management and labor, who face a difficult choice between cutting back health coverage or reducing wages or profits.

Small businesses are victimized the most. They pay twenty to thirty-five percent more than large firms for identical coverage. American corporations struggling to compete in world markets must bear health costs forty percent higher per capita than in Canada, ninety percent higher than in West Germany, and twice as high as in Japan.

These factors are contributing in turn to the increasing collapse of critical health care facilities in all parts of the country. Every private emergency room in Los Angeles that qualifies as a trauma center has closed its doors, because it can no longer afford to care for the most seriously injured accident victims. Public hospitals in New York City have three day waits to get into their emergency rooms. More than a third of rural hospitals are operating at a loss. Forty percent of all hospitals have safety deficiencies.

In addition to these four basic aspects of the crisis, drug abuse and AIDS are major complicating factors. The drug epidemic is creating a nationwide demand for treatment services and is exacerbating infant mortality. Hospitals in California are spending an additional \$500 million to one billion dollars a year to care for the stricken infants of drug dependent mothers.

The nation that spent \$1 billion to care for people with AIDS in 1986 will be spending \$2.9 billion this year and \$8.5



billion in 1991. In some urban hospitals, beds are already filled with AIDS babies and abandoned infants of drug abusers.

Realistic answers are available to stop this senseless slide and reform our health care system. The question is whether we have the political will to do so now, when reasonable remedies can make the difference, or whether we will wait until the current crisis becomes catastrophic and more drastic surgery is required. The cancer analogy is obvious. The longer we wait to deal with the disease, the more the infection spreads and the more difficult the cure becomes.

In my view, we should take four major steps as soon as possible.

First, we should require businesses to provide private, job-based insurance to all their employees. Most workers already get their insurance on their job; all businesses should provide it. It has been more than half a century since the nation decided that employers should be required to pay a minimum wage, to provide unemployment insurance and to participate in Social Security. As we enter the 1990's, the time is long overdue to require health insurance as well.

Requiring job-based health insurance is not unfair to business. The majority of businesses already do the right thing and insure their workers--and they are at a competitive disadvantage for doing so. They pay more for health care, because others pay less.

Second, we need to provide a public insurance program analogous to Medicaid for those who cannot get health insurance through a job. Premiums should be based on ability to pay. No American should be denied the fundamental human right to health care because they are unemployed.

Third, senior citizens and the disabled deserve the same affordable protection against the cost of long term care that Medicare provides against the cost of doctor and hospital care. No family should be reduced to poverty and no family nest egg should be wiped out by the cost of long term care,.

Medicare was the health issue for senior citizens in the 1960's--and long term care is the health issue for senior citizens in the 1990's.

There are some who say that we cannot afford these steps to protect all our people. I say that we cannot afford to ignore this crisis.

According to the non-partisan Congressional Budget Office, private insurance for workers and public coverage for the unemployed will add \$3.1 billion to Federal spending the year it is effective. That amount can be accommodated within the regular budget process without any special source of new revenues.

Long term care is more costly and will require new revenues. The Congressional Budget Office estimates that approximately \$21 billion a year in additional Federal expenditures will be needed. A realistic means of financing the program is to lift the \$50,000 cap on wages subject to existing Social Security and Medicare payroll taxes. The current cap is regressive and unfair. The wealthiest five per cent of employees--those earning more than \$50,000 a year--pay a lower proportion of their income to finance these programs than all other workers. Lifting this cap would raise more than \$40 billion a year, more than enough to finance long term care. The additional revenues could be used to reduce the level of the current payroll taxes.

The \$21 billion cost of long term care should be viewed in perspective of the current revenue gained by the Social Security and Medicare payroll taxes--\$330 billion a year. Long term care is affordable as part of Social Security and Medicare, and it can be financed in a way that makes these taxes fairer to all Americans.

Those who object to the costs of these programs ignore one fundamental fact: We pay for health care and long term care anyway, but we pay for them in cruel and irrational ways--by taxing the sick for their illness, by putting people in hospitals who could have been cared for in a doctor's office, by forcing senior citizens who want to remain at home into expensive nursing homes, and by condemning many of our children to early deaths or lives of disability.

Enactment of these three inter-related programs is the most effective step we can take to improve our health care system and to bring health care costs under control. Early outpatient care will reduce the need for expensive hospitalization. Home care will reduce the need for expensive nursing home care. Broad-based health insurance for all workers will cut health cost for

businesses that already provide it by as much as thirty percent. Reform of the insurance market will cut small business's costs by twenty-five percent. These savings will be immediate and by encouraging cost-effective systems of managed care and reducing unnecessary care, we can lay the foundation for additional cost-saving reforms in the longer term.

I have already introduced legislation to achieve these goals. In these hearings this week across the country, I am exploring the crisis as it affects diverse communities, discussing solutions, and attempting to build support for the changes we need.

According to a Gallup poll, eighty percent of the American people support universal health insurance along the lines I have proposed. The Heritage Foundation has endorsed a version of universal health care, and the American Medical Association now supports a plan like the one I favor. Similar majorities favor universal long term care insurance built on the model of Medicare and Social Security. Senate Majority Leader George Mitchell and House Speaker Tom Foley have placed health insurance at the top of the Congressional priority list for 1990.

I do not underestimate the difficulty of the task ahead. Powerful vested interests oppose the basic changes that are needed. But if Congress understands the problem and listens to the people, I believe we can succeed.

Nothing is written in concrete. I look forward to working with leaders in Congress, in the Administration, and around the country to achieve the broad-based support we need. The only thing that is unacceptable is to do nothing.

## BACKGROUND ON AMERICA'S HEALTH CARE CRISIS

The health care crisis facing the nation consists of four principal elements:

1. The large and growing number of uninsured and underinsured Americans;
2. The lack of affordable long term care insurance for senior citizens and the disabled;
3. The excessive burden of health care costs on businesses and workers; and
4. The failing financial condition of large numbers of hospitals and other institutions that provide essential health services to millions of Americans.

In addition, the health care crisis is affected by the problems of drug abuse and AIDS. These two epidemics present serious health issues in their own right, but they also exacerbate each of the four elements noted above.

## I. THE UNINSURED AND THE UNDERINSURED

According to the Census Bureau, more than 37 million Americans have no health insurance coverage, either public or private. This number has grown rapidly during the 1980's--from less than 30 million in 1979 to 37 million today.

The risk of becoming uninsured faces Americans of all ages and all economic levels. It is a problem for workers and non-workers alike.

Two-thirds of the uninsured--23 million--are workers or dependents of workers.

One third of the uninsured--12 million--are children.

Six hundred thousand uninsured pregnant women give birth annually.

3.6 million disabled Americans are uninsured.

Eleven million uninsured live in poverty.

Fifteen million uninsured have incomes that exceed twice the poverty level.



Seven million Americans who are insured would be deemed "medically uninsurable" by insurance companies if they lost their coverage for any reason.

Forty-eight per cent of the working uninsured are employed by small businesses with fewer than 25 employees (30 per cent of the total work force is employed by such businesses).

Twenty-three per cent of the working uninsured are employed by businesses with more than 1,000 employees (38 per cent of the total work force is employed by such businesses).

According to the Department of Health and Human Services, 60 million insured Americans have insurance that could prove inadequate in the event of serious illness.

According to surveys by the Robert Wood Johnson Foundation, one million Americans seek health care annually but are turned away because they cannot pay. Another fourteen million do not even look for care that they feel they need, because they know they cannot afford it.

Each year, according to the Department of Health and Human Services, 2.4 million families experience catastrophic out-of-pocket health care costs in excess of \$3,000 that insurance does not cover.

Two-thirds of the uninsured with serious health symptoms (such as spontaneous bleeding, loss of consciousness, unexplained weight loss) do not see a doctor for these symptoms.

The uninsured make forty per cent fewer physician visits than the insured; they are hospitalized 19 per cent less often, even though their average health is poorer.

A study in Washington, D.C., found that forty per cent of hospital admissions of uninsured patients (excluding obstetrics and trauma cases) could be avoided if primary care were available.

Sixty-three per cent of uninsured pregnant women fail to obtain adequate pre-natal care and contribute to the nation's high infant mortality. At 10.4 deaths per thousand babies in the first year of life, the United States has a higher infant mortality rate than nineteen other countries: Japan; Sweden; Finland; Switzerland; Canada; Ireland; the Netherlands; France; Denmark; West Germany; Norway; East Germany; Spain; Australia; the United Kingdom; Belgium; Italy; Austria; and New Zealand.

## II. THE LACK OF LONG-TERM CARE

2.9 million senior citizens are "severely disabled" and in need of long-term care, because they suffer from disabilities that require assistance to perform daily activities such as dressing, bathing, going to the bathroom, or eating.

1.3 million of these severely disabled elderly citizens reside in nursing homes today.

The other 1.6 million disabled elderly are struggling to survive in their own homes, in their children's homes, or in other community settings.

One million additional individuals under age 65 have comparable levels of disability.

As AIDS becomes a chronic illness, hundreds of thousands of young Americans will join the other severely disabled in need of long-term care.

According to a study by the Brookings Institution, forty per cent of today's senior citizens will be admitted to a nursing home at some point in their lives.

The number of persons 85 and older, the group at highest risk for long-term care, will increase five-fold over the next forty years, from 2.5 million to 12 million.

Without insurance coverage, long-term care is unaffordable for the vast majority of Americans. A recent study for the House Aging Committee found that:

--One-third of elderly couples and 50 per cent of single senior citizens would be impoverished after 26 weeks of nursing home care;

--50 per cent of elderly couples and two thirds of single senior citizens would be impoverished after a year of such care; and

--One-third of elderly couples and sixty per cent of single senior citizens would be impoverished after a year of home care.

The cost of nursing home care averages \$71 per day (\$26,000 a year), and exceeds \$100 a day in cases requiring intensive services.

Home care for a patient with Alzheimer's Disease care can exceed \$14,000 a year.

Only 4 percent of the elderly have long-term care insurance. A Pepper Commission staff analysis concludes that only seven percent of the elderly can afford private long-term care insurance. A Brookings Institution study concludes that private long-term care insurance is too expensive for most of the elderly. Forty-three per cent of the disabled elderly have incomes of less than \$9,000 per year.

Long-term care insurance for a seventy-nine year old would cost an estimated \$3000 a year.

Private long-term care insurance is more expensive than coverage under a government program. Under private Medigap coverage, 40 cents of the premium dollar is used to pay the insurance company's costs and profits; under Medicare, administrative costs are only two to three per cent.

### III. RISING COSTS OF HEALTH CARE

Between 1980 and 1987, nationwide expenditures for health care doubled, from \$248 billion to \$500 billion. The average annual increase was 10.5 per cent, more than twice the increase in wages. Per capita costs rose from \$1,054 to \$1,987 a year.

The share of GNP spent on health was 11.1 per cent in 1987, the highest in the world. The United States spends 40 per cent more per capita on health care than Canada, 90 per cent more than West Germany, and 100 per cent more than Japan.

Health care costs paid by business are 94 per cent of after-tax profits.

Businesses are shifting costs to workers in the form of higher premiums, higher deductibles, and higher co-payments. A recent survey by the Bureau of National Affairs found that 51 per cent of employers who require workers to contribute to health insurance premiums will seek to raise the contribution next year. Forty-one per cent of employers intend to raise deductibles.

Health costs are undermining the competitive position of American corporations. For example, Chrysler Corporation faces a built-in cost disadvantage compared to foreign firms of \$300 to \$500 per car because of higher U.S. health care costs.

### IV. FAILING FINANCIAL CONDITION OF HEALTH INSTITUTIONS

One-third of rural hospitals are operating at a loss.

One hundred urban hospitals (most of which are public hospitals) provide 40 per cent of the total charity care in the nation.

Half of all public hospitals are operating at a deficit, and the average deficit exceeds \$11 million.

Thirteen out of eighteen private hospitals in Los Angeles County have dropped out of the county's trauma care system--because emergency room patients suffering severe trauma are frequently uninsured. As a result, the burden of trauma care for the county's eight million citizens now falls entirely on 14 public hospitals.

According to the Joint Commission on Accreditation of Hospitals, 40 per cent of the nation's hospitals do not meet basic health and safety standards, largely because of inadequate financial resources.

#### V. THE ROLE OF AIDS AND DRUG ABUSE

Hospitals on the front lines of the drugs and AIDS epidemics are particularly hard-pressed. Four per cent of the nation's hospitals care for more than half of all AIDS patients. People with AIDS are nearly 3 times less likely to have private health insurance coverage than other Americans.

Some public hospitals in New York City hard hit by the AIDS and drugs epidemics have a three-day wait to get into their emergency rooms.

112,000 Americans have been diagnosed with AIDS, and 69,000 have died--more than the number of Americans killed in the Vietnam war.

During the next eighteen months, 100,000 more Americans will be diagnosed with AIDS.

1.5 million Americans are probably now infected with the AIDS virus.

In 1986, the cost of caring for people with AIDS was \$1 billion. Today, it is \$2.6 billion. By 1991, the cost will be \$8.5 billion.

Fifteen million Americans have used an illegal drug in the last month. According to the National Institute for Drug Abuse, four to six million Americans are addicted enough to drugs to require treatment. But enough drug treatment resources are available to treat only one in five addicts annually. Spending per addict treated has declined 40 per cent in real terms since the 1970's.



375,000 women giving birth each year have used illegal drugs during pregnancy. Their infants are at high risk of premature death, severe birth defects, high neo-natal care needs, and long-term learning disabilities.

The cost of caring for such infants will be \$500 million to \$1 billion a year in California alone. Eighteen per cent of the infants will be premature babies with severe complications, at a cost of \$135,000 a child for hospital care.

Two-thirds of hospitals serving large numbers of drug-addicted expectant mothers did not know of a place to refer these women for drug abuse treatment.

LEGISLATION INTRODUCED BY SENATOR KENNEDY  
ON THE HEALTH CARE CRISIS

I. THE BASIC HEALTH BENEFITS FOR ALL AMERICANS ACT (S. 768 / H.R. 1845)

All employers must provide a basic package of private health insurance benefits to full-time employees and their dependents. A phased-in public program is established to provide coverage to all other uninsured Americans by the year 2000.

PRIVATE JOB-BASED INSURANCE FOR WORKERS

Employees working 17.5 hours a week or more and their dependents are required to be covered. The employer must pay at least 80 per cent of the premium, except for low wage workers, where the employer pays 100 per cent. For employees working between 17.5 and 25 hours per week, the employer share of the premium is reduced in proportion to hours worked. Two-thirds of the currently uninsured (23 million people) will be covered by the job-based plan.

Benefits required to be provided include all medically necessary hospital care, physician care, diagnostic tests, pre-natal and well-baby care, and a limited mental health benefit. No exclusions from coverage because of pre-existing conditions are permitted. Deductibles may not exceed \$250 per individual and \$500 per family; co-payments cannot exceed 20 per cent. Each policy must include a catastrophic cap on out-of-pocket expenses for covered services of no more than \$3,000.

To promote flexibility in benefit design and minimize interference with existing employment-based coverage, employers may substitute alternative benefit packages, cost-sharing, and premium shares, as long as the package is actuarially equivalent to the statutory plan and the basic required benefits are included.

PUBLIC INSURANCE FOR OTHERS

The public plan offers coverage to all Americans who cannot obtain it through a job-based plan or an existing public program. A joint Federal-State program is created with Federal matching funds based on the existing Medicaid program. Premiums will be set according to ability to pay. The public plan will also subsidize co-payments and deductibles and the employee share of the premium for low income workers. Benefits are identical to those required under job-based plans.

Because of current budget pressures, the public plan is phased in. Beginning on the effective date of the bill, 4 million children and pregnant women below 185 per cent of the

poverty level will be covered. Phase II, implemented in 1996, will cover 5.7 million uninsured adults below 185 per cent of the poverty line. Phase III, implemented in 1999, will cover the remaining 4.3 million uninsured.

#### COST OF PLAN

The Congressional Budget Office estimates that the Federal cost of the plan will be \$3.1 billion in phase I-- \$1.8 billion for the public plan and \$1.3 billion for public costs associated with the private plan. CBO has not estimated the cost of the second and third phase, but costs should be comparable to phase I, for a total cost of about \$9 billion when fully implemented.

The job-based insurance mandated under the plan will cost businesses approximately \$18 billion a year including off-sets such as the reduction in current costs to employers of charitable and unreimbursed care. The cost per worker for coverage purchased through an HMO or other managed care plan is \$1,100 per year-- approximately \$4.00 a day.

#### SMALL BUSINESS INSURANCE

The plan reforms the insurance market for small business by establishing a system of competing private regional insurers offering the benefits of guaranteed coverage, economies of scale, and community rating. Regional insurers will be required to give small employers the opportunity to enroll in cost-effective managed systems of care such as HMOs and PPOs. These reforms can save small businesses an estimated 25 per cent of current premium costs--ten per cent in reduced charges for administration and sales costs; and fifteen per cent through participation in managed care.

Subsidies will be provided to small employers whose costs of compliance exceed five per cent of gross revenues. If the five per cent standard is found to be inappropriate for some industries, the Secretary of HHS is required to promulgate an equivalent standard.

The program will be phased in over five years for businesses with five employees or fewer. New small businesses with fewer than 10 employees may offer an alternative lower cost plan during their first four years in operation.

## COST CONTAINMENT FEATURES

The mandated benefits are constructed to permit employers to use all current cost-containment devices, such as managed care, pre-admission certification, and utilization review.

Employers who currently insure workers will receive reductions of up to 30 per cent in health costs as other firms begin to pay their fair share of the nation's health bill.

Small businesses will receive cost reductions of up to 25 per cent as the result of the regional insurance market reforms.

The regional insurer program will encourage the growth of cost-effective managed systems of care with the market power to promote system-wide change.

In order to provide national uniformity, state mandated benefit laws will be pre-empted by the federal plan.

Congress has recently enacted evaluation research and medical practice standards to eliminate unnecessary care and improve the quality of care. Other inflation-reducing steps that should be adopted include:

- Disclosure of cost and quality information by health care providers to assist insurers and consumers in choosing cost-effective care;
- Establishment of a national health care cost control review commission to analyze yearly cost increases, set voluntary cost increase targets for the upcoming year, and make annual recommendations to Congress, health care providers, businesses, and consumers for additional actions to reduce inflation.
- Demonstration grants to states wishing to develop innovative methods of controlling health care cost inflation.

## II. "LIFECARE"--THE LONG TERM CARE INSURANCE ACT OF 1988.

Lifecare covers home and community-based care and nursing home care for the elderly and disabled.

Persons eligible for assistance must be (1) totally dependent in at least one "age-appropriate activity of daily living" such as eating, dressing, bathing, toileting, or



transferring; (2) dependent upon assistance in at least two such activities; or (3) or cognitively impaired enough to require continual supervision.

The program is divided into Part A and Part B, like Medicare. Part A covers home care and the first six months of a nursing home stay, and is financed entirely by public funds. Part B covers longer nursing home stays, and is financed by public funds and private premiums. Enrollment in Part B is voluntary and can occur at age 45 or age 65.

#### HOME CARE PROGRAM

Benefits include: homemaker services; home health aid services; heavy chore services; adult day care; respite care; home mobility aids and minor home adaptations; nursing care; physical, occupational, and speech therapy; other services determined to be necessary by case a management agency.

The program is administered through states and local case management agencies, which assess the needs of the patients, develop plans of care with the patient and family, assist in arranging care delivery, and supervise care. The state or case management agency certifies agencies eligible to deliver care, establishes payment rates under Federal guidelines, and pays providers.

#### NURSING HOME CARE

Eligibility for nursing home care is based on the same disability standards as home care. Nursing home care is provided only if it is better for the patient and consistent with the patient's preference.

Care provided by nursing homes must be certified by the Secretary of Health and Human Services, who is to establish a prospective payment system for such care.

#### ADDITIONAL PROVISIONS

The bill also includes provisions to expand the supply and improve the quality of of long term care, by offering training for professionals; establishing centers to provide technical assistance to state and local agencies to conduct research; and providing consumer information on services.

## FINANCING

CBO estimates the additional Federal cost of the Lifecare plan at \$21 billion annually. The program is financed by eliminating the current cap of \$50,000 on wages currently subject to the Social Security and Medicare payroll tax. As applied, these taxes are regressive; all workers pay the same percentage rate of tax on the first \$50,000 of income and nothing thereafter. Eliminating the cap will raise over \$40 billion a year, of which \$21 billion will be used to finance Lifecare, and the remainder will be used to reduce the payroll tax.

STATEMENT BY DR. TED HOLLOWAY, DIRECTOR, SOUTHEAST HEALTH UNIT of the  
GEORGIA DEPARTMENT OF HUMAN RESOURCES

Access to medical care in our rural area of southeast Georgia has always been a problem for poor people. Death rates from cancer, cardio-vascular disease and other chronic diseases have exceeded the Georgia rates for many years. In the past few years, however, the number of people without any form of health insurance has dramatically increased as health care costs have escalated. More and more employers are cutting back on benefits and workers making minimum wages do not have the money to purchase insurance for themselves. Many families with severe health problems find insurance unavailable at almost any price. Now, the AIDS epidemic and the enormous health consequences of "crack" cocaine threaten to totally overwhelm us.

The Southeast Health Unit of the Georgia Department of Human Resources is comprised of 16 counties, encompassing an area approximately the size of the state of Massachusetts. This large rural area has a population of 274,000 people; over 45% of our white population and 78% of our black population live below 200% of the poverty level.

### Population Below 200% Poverty Level Southeast Health Unit



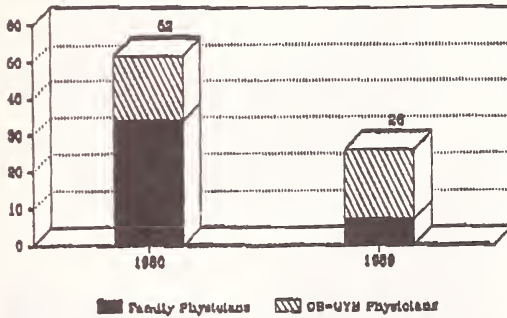
12/9/88

Changes in health care financing and lower Medicare reimbursement rates for rural areas have caused critical money problems for many of the smaller of our 14 hospitals. The "Health Care System" for this area was largely developed as a result of the Hill-Burton initiative after World War II. Fourteen of the 16 counties have hospitals which, in the past, provided health care for most of the people in the county. Only 2 or 3 of these hospitals continue to receive any county funding to provide indigent care. The rapid changes in health care financing, specialization and the rise of for-profit hospitals have placed intense competitive pressures on these

small hospitals. Hospital authorities are being forced to look at ways to limit indigent services, cease providing unprofitable types of care and try to attract private patients.

These changes in the health care system, along with the medical liability crisis, bode special consequences for maternal and infant services. Presently 12 of the hospitals provide OB care. It is difficult for a hospital that performs only 100 to 200 deliveries a year to afford the staffing, equipment and continuing education necessary to provide quality obstetrical and neonatal care. Private patients without the financial and transportation barriers that exist for the economically disadvantaged are traveling 50 to 60 miles to larger facilities for delivery. This results in further erosion of the financial base which keeps the small OB service in operation. Unfortunately, the larger hospitals in the area are not in a position to absorb the patients from the smaller hospitals. Six years ago, we had 52 physicians who were practicing obstetrics. Today this number has been reduced to 26 - 7 Family Physicians and 19 OB/GYN Specialists.

### Physicians Performing Deliveries Southeast Health Unit



12/7/89

Medical liability rates and the constant threat of being sued are causing many physicians to rethink their commitment to providing perinatal care. Family physicians who deliver 50 to 100 patients a year are finding it almost impossible to continue to provide this service.

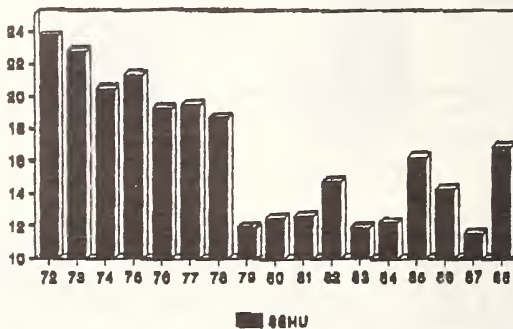
Low income pregnant women find themselves in a "Catch 22". They suffer more complications, have fewer financial resources to insure their health and welfare and are generally felt by physicians to be a high risk group for malpractice suits. The



hospitals, although willing in the past to accept indigent patients from their own county, do not want to open their doors to the indigent population from surrounding areas. Physicians are reluctant to provide prenatal care because the patients may not be able to afford the medications, monitoring and special tests that may be necessary. More and more women are presenting to Emergency Rooms for delivery with no prior arrangements for the physician or hospital care.

We face some grim realities. Twenty percent of our white infants and one out of three of our black infants are born to teenage mothers. Our medical community estimates that as many as 5 to 10% of our prenatales are using crack! Surveys done in late 1988 in Georgia confirm that 2 out of every 1,000 live births are to HIV positive women. In some areas, the rate already is twice that figure! The number of infants who weighed less than 500 grams at birth in our area increased threefold in 1988. We attribute much of this increase to the use of crack. Early in the pregnancy, there is an increased risk of spontaneous abortion and later the risks of abruptio placentas and premature delivery are increased. Infants of women who used crack during their prenatal period tend to have lower birth weights and smaller head circumferences. Sudden Infant Death Syndrome is 10 times more likely in cocaine babies. Our Infant Mortality Rate jumped to over 16 deaths per 1,000 live births in 1988 - the highest rate we have had in over a decade!

Georgia and Southeast Health Unit  
Infant Deaths per 1,000 Live Births



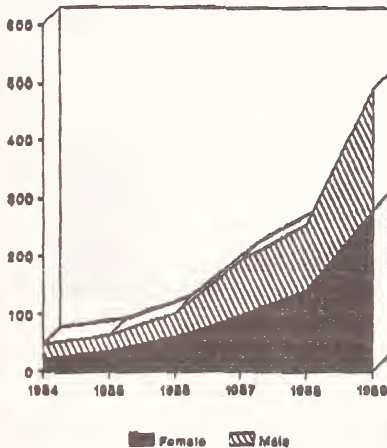
Total Infant Mortality Rate

More is being learned about the long term effects of prenatal cocaine exposure. These infants have trouble bonding and are subjected to increased abuse and neglect. Studies by

Dr. Ira Chasnoff's group in Chicago have shown that pre-school children whose mothers used cocaine while they were pregnant have a significant increase in attention deficit disorders and learning disabilities. Our educational system faces an unwanted challenge when these children enter kindergarten in 5 years!

A syphilis epidemic, unprecedented since the introduction of penicillin, has exploded in rural southeast Georgia because of crack. In 1984 there were only 48 new cases of syphilis in the 16 counties of the Southeast Health Unit. During the first 11 months of 1989 this number has increased almost 1000% to 451 cases.

**Syphilis Cases 1984 to 1988**  
Southeast Health Unit



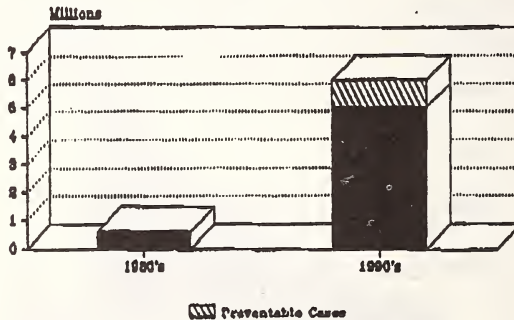
SEHU 12/04/89

over 60% of these cases are females. Congenital syphilis is on the rise all over the state. We are currently following up 6 cases in my area alone. Most of the people with syphilis report involvement with crack or having sex with someone who uses crack. It is not unusual to find that these individuals have over 30 to 40 recent sexual contacts. Trading sex for drugs and having multiple (often anonymous) partners is common among people using crack. Drug dealers often target young females in marketing their drugs. Once the young woman is addicted, she becomes either a dealer or prostitute to support her habit. Some of these individuals

are also HIV positive. The combination of genital ulcers and sex with many individuals are the ingredients needed for the AIDS epidemic.

Johnathan Mann, M.D., Director, Global Programme on AIDS for the World Health Organization states, "The worldwide epidemic of human immunodeficiency virus (HIV) infection and AIDS started silently during the mid-1970's. By 1981, when AIDS was first described in the United States, HIV had already spread to five continents. In the mid-1980's, recognition of the global scope of the epidemic was accompanied by legitimate fears of an uncontrolled epidemic. During this decade, over 5 million people became infected with HIV, about 600,000 people developed AIDS and over 300,000 died.... "

### Worldwide Adult AIDS Cases World Health Organization Projection



During the decade of the 1990's, it is estimated that cases worldwide will exceed 6 million - that's 10 times the number of cases we've had so far! How can Georgia provide care for 30,000 people with AIDS and many times that number of HIV infected individuals? Over the next 10 years, virtually every person in the United States will personally know someone infected with HIV. Remember, we only had 154,000 cases of paralytic polio in the United States during the 1950-1954 epidemic. Almost everyone who lived through those terrifying times knows several people who were paralyzed by this virus. The Human Immunodeficiency Virus may cause AIDS in over 1,000,000 Americans in the next 10 years.

New treatment guidelines offer hope for a much improved

quality of life and survival. Studies giving low doses of AZT per day to HIV positive individuals before they have advanced to AIDS (T4 counts between 200 and 500) have shown encouraging results in preventing or slowing the progression of the disease. Full dose AZT for people with T4 counts below 200 continues to be a standard of care. Prophylactic aerosol pentamidine to prevent *Pneumocystis carinii* pneumonia (PCP) has been shown to be effective in decreasing recurrences and primary infections. Many other drugs are in various stages of testing and offer promise. Combination therapy may increase effectiveness and decrease side-effects. Early recognition and aggressive treatment of toxoplasmosis, esophageal candidiasis and other serious infections are now standard therapies.

Unfortunately, there are few people in rural Georgia who can afford this disease. What is considered standard therapy is out of reach for most people in Georgia who do not have insurance, medicaid, or live close enough to an urban center which provides services for people living with HIV infection. I have talked with families struggling to get AZT and pentamidine for their loved ones. I have been seeing patients that can not afford their medicines. Doctors have called to ask if we have money for medications and laboratory tests that their patients critically need. I've talked to people who were afraid to use their health insurance for fear of losing their jobs, yet they can not afford \$1,000 a month for medication any other way. Last week I held the hand of a dying young man who lost his medicaid coverage because his disability insurance exceeded the "limit" by \$50 a month. It is incredible to me that the only people in our rural areas who are able to get these medications, regardless of their ability to pay, are those who are in prison!

We must realize that HIV infection is a treatable chronic disease. Systems must be put in place to provide affordable outpatient care and medications in our rural areas. It has been shown conclusively in San Francisco, Atlanta and other cities that this type of care is much cheaper than relying on a system that is inpatient based. Failure to do this will result in financial chaos for our ailing hospital system as patients go to emergency rooms and local hospitals in crisis. It will result in the continued suffering of thousands of HIV infected individuals and their families who can not afford medical care.

Long assumed to be an urban problem, crack cocaine has invaded the rural area of southeast Georgia with a vengeance. In the past four years, drug related offenses by juveniles have increased 80%. Child abuse and neglect, secondary to crack addicted parents, have become common. The State supported Alcohol and Drug Treatment Centers in Waycross and Statesboro have been overwhelmed with young males and females addicted to crack.



There is a great need for expanding services for people with substance abuse problems. In a very short time our patient population has changed from largely middle aged White males with alcohol abuse as their primary drug to young males and females, Black and White, who use crack and other drugs. We are beginning to see many pregnant women who are addicted to crack. Half of the infants in Atlanta's Grady Hospital Neonatal Intensive Care Unit are "snow babies". Inpatient services for addicted pregnant women, however, are difficult to find. Some sort of supervised residential programs may be needed to let women live in a drug free environment during their pregnancy. Our programs will have to radically change treatment approaches to deal with these major shifts.

Special emphasis must be placed on improving availability and accessibility of substance abuse services for adolescents. The 14 year old pregnant girl with syphilis, on crack and in trouble with the law is all too common. Our Regional Youth Development Centers report a sixty percent increase in admissions of substance abusers over the past four years. The Georgia Bureau of Investigation reports that juvenile arrests for alcohol and/or drug related offenses have almost doubled since 1984 (from 2,795 to 5,349).

Crack has impacted low income areas especially hard. Programs are needed to help mobilize and empower residents of housing projects and other areas that have become major centers of the drug trade. In the past, we have not been very successful in combating the drug and alcohol problems of the Black community. If we hope to keep people from going back to dealing as a way of life, literacy and job skills will need to become a part of treatment. Something must be done to increase job opportunities for Black men and women.

We must learn all we can about those three inextricably linked problems, syphilis, crack and AIDS, if we are to be successful in dealing with these new threats to society. The victims of this triad are our friends, neighbors, and children. Crack use is expanding in all segments of our community, especially among those from 18 to 30 years of age. It is said that the desire to use crack is so powerful that many people are "hooked" after just trying it one time. Would you have been one of the unlucky ones to try crack, just one time, if it had been around when you were young? What can we do to keep our kids from starting to use drugs? How can we best treat those already addicted? Can we stop the explosion of sexually transmitted infections spawned by crack? Will "sex for drugs" and the promiscuity of crack users hasten the spread of the HIV virus and thus usher in a new wave of the AIDS epidemic? What will be the response of the community? Can we afford to allocate the necessary federal, state, county, city, and private resources to meet

this challenge? Can we afford not to? Racism, poverty, homelessness, alienation from society, unemployment and hopelessness are all factors in our drug problem. The War on Drugs must be fought on many fronts. There are no easy answers. We must mobilize the conscience of our Nation for the fight. This is a War that we cannot afford to lose.

Hospitals in our area are being forced to decrease services which lose money in order to keep their doors open. Private For-Profit Corporations have little interest in providing care for uninsured patients. Our private physicians are faced, on the one hand, with pressure from their hospitals to hold down costs which are not reimbursable and, on the other, with ethical and medico-legal obligations to provide quality medical care to their patients regardless of income. The expansion of medicaid benefits to more pregnant women and children is an important step. It comes at a time, however, when our present health care financing system is breaking down. Rising numbers of uninsured working men and women are finding it impossible to get routine medical care for their families. Migrant laborers, whose numbers have greatly increased in Georgia over the past few years, are woefully underserved. The one small federally funded migrant health project in Georgia is only able to offer limited outpatient services. It serves only 4 counties and has had virtually flat funding for 5 years. The aging of America and the absolute dearth of long term care options is frightening. Aging parents live in fear of what will happen to their mentally ill or mentally retarded children when they die. They have seen far too many who find themselves homeless after they have been discharged from nursing homes or public institutions. It is virtually impossible to get long term residential care for even the most severe cases. Added to this growing number of people without basic shelter, food and health care are the HIV positive people who lose jobs, homes and health care because they are sick.

Medical care in America is increasingly becoming a privilege rather than a right. The quality of care provided for those who are privileged to be in the system is unparalleled in the industrialized world. Unfortunately, for the increasing numbers of people left out of the system, access to health care is more like that found in a developing country. The problems we face demand answers. Major changes in the way we provide health care in the United States must take place. Being poor, having an "expensive" disease, growing old - should these be reasons for people to be denied basic needs? We in south Georgia think not. This land was founded because a few courageous souls dared to believe that life could be better for every person, no matter what his or her circumstances. As we enter the last decade of this century, we are challenged as never before to uphold these beliefs. We can settle for nothing less!

Ted Holloway, M.D.

The CHAIRMAN. In wrapping up, I want to thank all of you. You have been extremely kind and patient in the course of our hearing. It has been an extremely moving hearing, a hearing from the heart, a great deal of emotion and a great deal of challenge.

As I indicated at the beginning of the hearing, this is the last stop in a 4-day tour and during the course of the tour, we started up in the northeast, at Bronx, New York; Los Angeles and the West Coast; St. Louis, in the industrial heartland, and finally came to Sparta, in the rural South. At every stop, we found the same story, a health care system that is failing to give hardworking people the kind of protection that they need and deserve, and that is really in a state of collapse that threatens the health of every American. I believe the American people know it is time for a change. In the 1930's we enacted Social Security, in the 1960's we enacted Medicare and I am very hopeful that in the 1990's we can enact a program that makes health care a basic human right for all Americans in the rural parts of this country, all parts of our Nation for every family. [Applause.]

I want to thank Dr. Green for his statement. To Johnny Warren, the development director of Hancock County, Katherine Hill, the tourism director of Hancock County, Sistie Hudson, our Sparta mayor, she has been extremely accommodating and helpful, Betty Hill who is the chair of the County Commission, we are grateful to her, Dulcie Moore and Dr. Guy at the Primary Health Care Clinic, they spent time with us, welcomed us and have been enormously valuable.

And most of all I want to thank my hosts here, Donna and David Griffith, they were kind enough to offer their home to me last evening and even perhaps more impressive their heart and their friendship and I am enormously grateful to them. I got a real insight into the hospitality of Sparta, GA through them and I am very grateful to them.

I thank all of you for your courtesy and your patience, and our committee stands in recess.

Thank you. [Applause.]

[Whereupon, at 12:20 p.m., the committee adjourned, subject to the call of the chair.]

CMS Library  
C2-07-13  
7500 Security Blvd.  
Baltimore, Maryland 21244



CMS LIBRARY



3 8095 00007887 9